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## Provider perspectives on shared decision-making regarding hypospadias surgery

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#### Summary

**Introduction**—Many parents experience decisional conflict and decisional regret around hypospadias surgery. The utilization of a shared decision-making (SDM) process may mitigate these issues, however addressing the principal components of the SDM process is a complex task that requires the investment of providers.

**Objective**—The purpose of this study was to facilitate a discussion about SDM anchored on hypospadias with pediatric urology and general pediatric providers to explore perspectives, clinical applications and barriers to adopting SDM in clinical practice.

**Study design**—We conducted two focus groups in order to engage pediatric urology and general pediatric providers in guided discussions about SDM anchored on hypospadias. All activities were audio recorded and professionally transcribed. The transcripts were analyzed by three coders using directed qualitative content analysis techniques to identify themes and relationships between themes to inform the development of an affinity diagram (Extended Summary Figure).

**Results**—Two focus groups were held; one with seven pediatric urology providers in November 2018 and one with ten general pediatric providers in January 2019 (median age 51 years, 88.2% Caucasian, 58.8% female, 70.6% physicians and 29.4% nurse practitioners). Both groups identified some of the key components of SDM including engaging families in decision-making, informing them about treatment options and clarifying values/preferences (Extended Summary Figure). They thought that SDM was useful for discussing preference-sensitive conditions (e.g. hypospadias) and addressing parental compliance. General pediatric providers also suggested that SDM helped them avoid unnecessary referrals to specialists. Both groups identified

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parental, provider and systemic barriers to the adoption of SDM: a) desire for paternalism, b) misperceptions about medical evidence, c) completion of parental decision-making prior to the clinical visit, d) provider bias/lack of interest and e) time constraints/productivity pressures.

**Discussion**—Providers who care for hypospadias patients are knowledgeable about SDM and its potential clinical applications. They identified several potentially modifiable barriers to the adoption of a SDM process about hypospadias surgery in a pediatric clinical setting.

**Conclusions**—Based on feedback from providers, we plan to implement a hypospadias decision aid early in the parental decision-making process about hypospadias such as in the postpartum unit and at well-child visits in the newborn period and provide a provider training session about SDM to address the identified knowledge gaps.

#### **Summary Figure**



Affinity map of provider perspectives on shared decision-making: components, applications and barriers. Red = pediatric urology providers. Blue = general pediatric providers. Purple = both groups.

#### Keywords

Hypospadias; Focus group; Decision-making

#### Introduction

Many parents experience decisional conflict (DC) and decisional regret (DR) around hypospadias surgery [1,2]. The utilization of a shared decision-making (SDM) process may mitigate these issues by addressing unmet decisional needs. SDM is the process of making healthcare decisions using a bi-directional flow of information incorporating the best available evidence and the family's preferences. [3] Decision aids (DA) are tools designed to facilitate SDM but providers and families may also engage in SDM without the use of DAs.

Addressing the principal components of the SDM process is a complex task that requires the investment of parents and providers. As part of a multi-year project focused on the development of a hypospadias DA for parents, we explored parental preferences and priorities regarding hypospadias decision-making and engaged them in the codesign of a hypospadias DA prototype [4]. Parents desire a hypospadias DA that addresses common, specific knowledge gaps and is customizable to their specific concerns and informational needs. The current study was planned *a priori* in order to explore providers' perspectives about SDM in pediatric practice anchored on hypospadias. In the context of our planned scope of work, we sought to identify potential barriers to the utilization of SDM in clinical practice in order to inform our strategy for pilottesting the hypospadias DA in the clinical setting. Therefore, the purpose of this study was to facilitate a discussion about

SDM anchored on hypospadias with pediatric urology and general pediatric providers to explore their perspectives about SDM, clinical applications of SDM and potential barriers to adopting an SDM approach in clinical practice prior to pilot-testing the hypospadias DA in the clinical setting.

#### Materials and methods

#### Study participants

We recruited a convenience sample of pediatric urology providers, including attending physicians, fellows and nurse practitioners, from our academic medical center via email. We excluded residents, medical and nursing students because of their presumed limited experience with SDM in clinical practice. We recruited a convenience sample of general pediatric providers from a list of 49 registrants for a pediatric continuing medical education (CME) conference at our academic medical center in January 2019. This quarterly conference typically attracts a statewide audience of pediatric primary care providers. We contacted providers via email on two separate occasions, one week apart, to discuss study participation and obtained informed consent. The study was reviewed and approved by our Institutional Review Board.

#### **Data collection**

Two focus groups with pediatric urology and general pediatric providers were conducted in November 2018 and January 2019 respectively at our academic medical center during existing academic/CME activities in order to maximize the number of participants and minimize their absence from patient care. We used a convenience sample due to the availability and ease of access of the providers.

Our approach was qualitative in nature and informed by human-centered design methodologies. Human-centered design is a form of qualitative research that includes elements from product development and participatory design, using abductive reasoning to start with a set of observations and find the simplest and most likely explanation for these observations [5]. Key practice components of human-centered design are building empathy, thinking by doing, making things visual, combining divergent and convergent approaches, and fostering collaboration and empowerment amongst stakeholders [6]. Human-centered design is appropriate to this work because it uses qualitative guided group discussion as

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one of its methods and because human-centered design will continue to be an appropriate approach as we move toward designing a tool.

The facilitation team consisted of two human-centered design researchers (one male, one female) who had no prior relationship with all but three of the participants. They have a Master Degree in Human-centered Design Research and a Bachelor of Fine Arts in Visual Communication Design respectively and approximately 10 years of experience planning research activities, facilitating group discussions and collaborative activities and analyzing data [7]. They limited their own biases by acknowledging potential bias and unique perspectives of the team members, asking open-ended questions of participants, emphasizing process during both data collection and analysis, having empathy for participants and genuine appreciation for their input, using multiple coders during analysis, and involving peers in the research design and discussion of findings.

A multi-disciplinary team with expertise in communication design, pediatric urology, and health services research developed the focus group guide based on previously identified themes from our interviews with parents, expert consultation and a review of the literature on provider perspectives about SDM (Table 1). Objective evidence of shared decision-making behavior during clinical encounters is lacking and there are heterogeneous approaches to communication and decision-making between physicians and families[8–10]. In addition, providers frequently cite barriers to SDM such as time commitment, interruptions in workflow/continuity of care and lack of skill for SDM [11]. Therefore, we asked providers to define SDM and discuss its key components and potential applications to hypospadias decision-making as well as other conditions. We also asked them to identify specific barriers to adopting SDM in clinical practice. The discussion about SDM was anchored on hypospadias but the conversation naturally evolved to include a general discussion about SDM in clinical practice.

All activities were audio recorded, professionally transcribed and participants' responses were de-identified with the exception of gender. Transcripts were reviewed for accuracy prior to data analysis. Two members of the research team took extensive field notes during the focus groups. Each session lasted approximately 90 min and participants were compensated \$50.

#### Data analysis

Transcripts were professionally transcribed and imported into NVivo Pro qualitative research software (version 12, QSR International Pty, Ltd., Doncaster, Victoria, Australia) to facilitate grouping, sorting and cross-referencing of the data. Our multi-disciplinary team of three coders independently categorized (i.e. double coded) textual data, including transcripts and field notes, using directed qualitative content analysis techniques [12]. Initial codes were generated by first highlighting words from the text that capture key thoughts or concepts. Next, labels for codes emerged that were reflective of more than one key thought. Codes were then sorted into categories based on how different codes were related and these emergent categories were used to organize and group codes into meaningful clusters or themes within each domain of the focus group (i.e. perspectives, clinical applications and barriers). Team members resolved discrepancies and reached consensus about the major

themes and subthemes that were common to both focus groups. Data saturation was confirmed by examining the themes to determine that no new themes emerged. Next, we created an affinity diagram demonstrating key themes and relationships between themes from the focus group (Extended Summary Figure) [13].

#### Results

#### Demographics

Of the 49 pediatric conference attendees, 10 (20.4%) agreed to participate: median age 52.5 years, 80% Caucasian, 80% female, 70% physicians and 30% nurse practitioners. We did not inquire about reasons for nonparticipation. Of the 12 eligible pediatric urology providers, 7(53.8%) agreed to participate: median age 38 years, 100% Caucasian, 71.4% male, 71.4% physicians and 28.6% nurse practitioners. Non-participants were either on vacation or off-site at satellite clinics. We compared the characteristics (gender, type of degree) of participants versus non-participants using Fisher exact tests and noted no significant differences. The pediatric CME conference did not collect any additional demographic data on registrants thus we were unable to compare race/ ethnicity or age.

#### Perspectives about shared decision-making

Both groups identified key components of SDM: a) engaging families in decision-making, b) informing them about treatment options and c) clarifying values and preferences (Table 2) [14]. Pediatric urology providers estimate the parents' educational background in order to tailor their presentation of clinical information: "I think you talk to different patients differently. There are certain patients who come in whose parents are engineers. It's a much different conversation than other patients with perhaps less education. It's not that you're giving them less information. It's how you present the information." General pediatric providers suggested that SDM gives families control: "sometimes it seems that it's uncontrollable, if kids are sick or there's a bigger issue going on that they don't understand fully .... that's when I think parents get really anxious ... shared decision-making helps that parent feel in control."

#### Clinical applications of shared decision-making

Both groups suggested that SDM is useful for discussing preference-sensitive conditions and addressing parental compliance with provider recommendations (Table 3). Both groups recognized that certain types of medical decisions are better suited to an SDM approach. A pediatric urology provider stated, "a lot of the procedures I see are simple things like, 'fix this' versus some of the things that Dr. X might be seeing are certainly more nuanced, controversial and there's a lot more discussion going on. Shared decision-making is definitely procedure-dependent." General pediatric providers use SDM to discuss mental health referrals and medications: "I find that you have to spend a lot of time walking through people's cultural understanding of mental health … and we have to respect the family's position on whatever it might be. You can prescribe the medication but they may choose not to take it if you don't do a good job in bringing them along to what the options and the outcomes will be." General pediatric providers use SDM to discuss intervention versus

watchful waiting with families: "I just try to listen and understand what the families want. It's a lot of watchful waiting versus intervention. Sometimes it might be a slightly better option but if they feel talked into a watchful waiting situation they're not going to be settled in that decision whereas if we take their opinion into consideration, watchful waiting oftentimes feels good to them." In addition, general pediatric providers use SDM to avoid unnecessary referrals: "I feel a lot of [shared decision-making] is whether a patient really needs a referral or not. That's where I can say, 'I really think this is probably something we can watch, but if you would like a referral to a specialist to have a further discussion about this, that is completely reasonable." Pediatric urology providers use an SDM approach when they discuss challenging cases with each other: "I've used shared decision making not only as patient-physician shared decision making but we just had a conference of shared decision-making. The amount of information out there is enormous and sharing not only that information but experience in trying to get the parents' input is critical in today's world."

#### Barriers to implementation of shared decision-making

Both groups identified parent- and provider- and system-related barriers to the adoption of SDM (Table 4). Providers suggested that some parents desire a paternalistic approach to medical decision-making, seeking the provider's opinion about the best management options. Other parents complete most of their decision-making process prior to the clinical encounter with minimal input from the provider. Providers acknowledged their own biases about SDM in addition to time and productivity pressures that limit their ability to engage in SDM: "I think we have time constraints today and the great gorilla in the closet is that we are under practice guidelines where we are seeing patients every 15 or 20 min. These are time-consuming discussions to actually get to an endpoint that feels very satisfying to the patient/family and the provider ... you learn how to construct that 15—20 min into a good shared decision."

Pediatric urology providers noted that parents may receive inaccurate medical information from other healthcare providers: "I see a lot of patients who are told something by another physician who is not in our specialty ... and you have to come in and undo what someone else has done. That's another part of shared decision with the families is to break down their trust relationship with their pediatrician or ER physician and rebuild it back with you." General pediatric providers noted that intense emotions may be another barrier to SDM: "When they don't have such intense emotions about something it's easier to share [the decision]. I've found a few times where ... their intense emotion isn't necessarily based on Facebook but it's that anxiety of, 'something's happening and I don't know what it is."

#### Discussion

We found that the providers who participated in our study were knowledgeable about SDM and its potential clinical applications. Although there are many conceptual definitions of SDM, essential elements of the SDM process include: a) explicitly deciding to address the problem; b) presenting options, pros and cons including the communication of quantitative risk information; c) assessing patient's values, preferences and abilities; d) verifying patient's understanding; and e) making or explicitly deferring the decision [14]. The

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providers in our study identified a number of these essential elements (e.g. presenting options, pros and cons and assessing values/preferences) but they omitted other elements such as communicating quantitative risk information and verifying patients' understanding. They also suggested novel applications of SDM, such as physician-to-physician SDM in the setting of academic case conferences. Given these knowledge gaps, providers may benefit from targeted interventions to improve their understanding of SDM prior to introduction of DAs in clinical practice.

Pediatric SDM raises unique challenges given that parents and other caregivers may also have a vested interest in the decision and bring different personal values or preferences into the equation. Based on our prior work regarding parental perspectives, parents must act as proxy decision-makers on behalf of their sons which may contribute to their anxiety during the decision-making process [4]. In other medical conditions, children are involved in decision-making on a spectrum that evolves as they age and mature [15]. Interestingly the providers in our study did not discuss the involvement of their pediatric patients in the SDM process even when discussing conditions other than hypospadias. This reflects the findings of a recent systematic review by Wyatt and colleagues who noted the majority of SDM interventions in pediatrics targeted the parents alone while only about a quarter of them targeted the pediatric patient with or without other parties (e.g. parent or provider) [15]. The most common clinical scenarios for SDM interventions included immunization, attentiondeficit/hyperactivity disorder and acute respiratory tract infection [15]. Other pediatric subspecialties such as otolaryngology face similar challenges regarding decision-making [10]. Boss et al identified that information sharing and parent engagement are important aspects of decision-making and that personal, social and cultural factors may impact the decision-making process [10].

Providers identified a wide variety of clinical applications for SDM and emphasized that the appropriateness of an SDM approach may depend on the preference-sensitive nature and/or complexity of a given condition. For example, they recognized the value of using SDM to discuss vaccines with families. This may seem counterintuitive given that routine vaccination is not considered to be "preference-sensitive" but general pediatricians our study utilized an SDM approach to negotiate an alternative vaccination schedule with parents in order to improve vaccine compliance.

Providers identified multiple barriers to the implementation of pediatric SDM including a perceived desire for paternalism, misconceptions about medical evidence, completion of the decision-making process prior to the clinical visit, intense emotions, provider bias/ lack of interest and time/productivity pressures. In a recent systematic review, Boland and colleagues categorized barriers to pediatric SDM at the: a) decision level (e.g. perceived lack of options) b) innovation level (e.g. poor quality information) b) adopter level (e.g. parent/child emotional state), c) relational level (e.g. power imbalance) and d) environmental level (e.g. insufficient time) [11]. Parent/child emotional state was the most commonly reported barrier at the "adopter level" with specific concerns about parents/children feeling overwhelmed, in denial, defensive or anxious. Healthcare professionals cited insufficient time due to heavy workloads as the main environmental barrier to SDM [11]. Clinic workflow (e.g. integrating SDM into the care pathway) and poor continuity of care (e.g. high

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staff turnover) were reported to hinder SDM [11]. At the relational level, parents, children and healthcare professionals noted that deliberately biasing the opinion of others (e.g. giving a specific recommendation) undermined the SDM process. These adopter, environmental and relational-level barriers to SDM are similar to those identified by the pediatric providers in our study such as intense emotions, productivity pressures, limited time for clinical visits and provider bias/lack of interest.

One limitation of this study is that the small population sampled limits generalizability and our findings may not reflect the views of all providers who care for hypospadias patients. We recruited general pediatric providers from a statewide pediatric conference, however, in order to maximize the diversity of viewpoints about pediatric care. Our response rate of approximately 20% amongst pediatric providers is typical of the low response rates in physician surveys [16,17]. The pediatric providers who participated in our study practice in an outpatient clinic setting rather than a newborn nursery and this may limit their exposure to discussions about hypospadias decision-making. We plan to include neonatal providers in future phases of the study given that are important stakeholders in the decision-making process about hypospadias.

Another limitation of this study is the potential loss of visual data (e.g. intonations of voice, body language and seating arrangements) during analysis of workshop transcripts such as that can add meaning to the textual data [18]. This seems unlikely in this case given that three of the authors were present for both focus groups and took notes during the sessions.

In the context of hypospadias outcomes research, this study provided valuable information about the optimal timing and settings for the introduction of decision support tools such as DAs. Based on feedback from providers and parents about potential barriers to implementation of SDM and timing of the parental information-seeking process respectively, we plan to introduce the DA in the postpartum unit and at well-child visits in the newborn period. We hope this will provide families with high quality information about the condition early in the decision-making process about hypospadias and minimize the time burden for specialists during clinical visits. In addition, we plan to conduct an educational session with providers about the potential benefits of SDM including improving decision quality and decreasing decisional conflict and regret [19,20]. We hope that careful attention to time constraints, provider knowledge gaps and parental misperceptions of medical evidence will maximize the success of DA implementation. In future studies, we plan to conduct alphatesting of the DA prototype in a controlled research setting followed by beta-testing in a "real-world" setting in order to obtain feedback on the DA prior to launching a pilot test in the clinical setting.

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#### Table 1

Proposed topics and guiding questions for provider focus groups.

Торіс	Guiding Questions and Prompts
Introduction	"Today we are here to learn about hypospadias and decision-making with parents. We've already done some work with parents and got some good insights from that. Now we're here to learn from all of you. A few rules before we get started We want this to be a place where everyone feels comfortable participating so we don't criticize other ideas. There aren't any right or wrong answers and you can pass if you don't feel comfortable saying anything. We try to be open and constructive. Don't be afraid of sharing your ideas or building on the thoughts of other people. Please stay focused on the topics and activities and try to have fun. Any questions before we get started?"
Icebreaker	"Please introduce yourself, pull a 'gift' out of thin air and hand it to the person next to you. They will accept the 'gift' and then say, 'thank you. You got me X.' They should say the first thing that comes to mind."
Shared decision- making: definition	"We're going to talk about shared decision making. Is everyone familiar with shared decision making? Can anyone share their definition of it in the context of healthcare and working with patients and their families?"
Shared decision- making: perceptions	"What are your perceptions of shared decision making?"
Shared decision- making: experiences and personal significance	"Does anyone have any other definitions or experience with it? What it means to them"
Shared decision- making: clinical applications	"Is anyone using shared decision making in their practice actively? Could you talk a little bit about that?"
Shared decision- making: barriers	"What are some potential barriers to using shared decision-making in your clinical practice?"
Information provision vs. seeking	"So when you are having discussions about hypospadias, for example, do you direct parents towards information or does all of the information come from you?"
Decision support	"How do you help parents make decisions if they just can't make a decision? Does that ever happen with hypospadias, for example?" "Is there anything you do to intentionally give parents control or is that something you think about, giving them control over a decision?"

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## Table 2

Representative quotes from general pediatric and pediatric urology providers about the components of shared decision-making.

	General pediatric providers	Pediatric urology providers
Values clarification	"Shared decision making [is] applied to decisions where there truly is a choice of what is the best answer [for] your patient and family and so you want to find out what matters to them, what's important to them to inform them on it and to help guide them based on their preferences, what decision might be appropriate." (M) "You have guidelines that make recommendations on how you ought to approach different conditions.	"The big component is listening to parents' preferences, beliefs, what is it that they want you to do, what were they thinking before you got into the room? So, just to find out what it is that they want, how that interplays into the information that you're providing." (M)
Information delivery	I will deliver that information to the family and see how they feel and see what their thoughts are and have that be an open conversation with them about what is recommended, what has good outcomes." (F)	"As surgeons we look at shared decision making as an opportunity to tell the parents something about their underlying disease and try to get them informed so they can understand how we create that decision about opportunities to help them with that disease. We do that every day essentially in surgery because you have to inform the parent about what their options are in our field." (M)
Active engagement in decision- making	"[Shared decision-making means that you] just have families actively engage in the ultimate decision of how to proceed forward with any number of things in the clinical setting." (F)	"When you're seeking information [as a patient], at the end of your information gathering. I think a lot of times you want the expert to make the decision jointly with you, but you want them to tell you sometimes what's the best thing to do even after you're completely informed." (M)

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# Table 3

Representative quotes from general pediatric and pediatric urology providers about the clinical applications of shared decision-making.

	General pediatric providers	Pediatric urology providers
Discussing preference- sensitive conditions	"There are different levels of [shared decision-making] based on something you're talking about, conditions or medications versus something like discipline or bedtime. There are different levels of control or the 'shared-ness'. You want openness of who makes the decisions and how we feel about the decisions and things that need to happen like medicadions versus the options you want to take to discipline your child versus like there's no right or wrong. So those other things kind of flavel major fleets down the road or could have potential side effects. So, it depends on how the priority of where it is on their health and their future and all this kind of stuff." (F)	"I look at it as black, white and gray. The white answer is that just want your affirmation that nothing needs to be done. The black, they know something needs to be done and it's a fairly quick decision make About 80% of what we do is in the middle. It's gray. There are a lot of options on how these things can be managed, anywhere from doing nothing to minimal to fairly major procedures that you can do. That's really where the shared decision making gets more difficult for us because 1) we don't always have the black and white tanswer and so it takes longer to describe nebulous decision making, right? The black and white things are really easy. I think." (M)
Addressing compliance	"There's a lot of times I have families that come that want immunizations; they just don't want five at one time. Some of that shared decision making is okay [in order to] come up with a plan [their] child needs to be immunized and they're not against that per se. They're against putting four shots in their child's body at one time. So, how can we come to a decision? I can give you the data [about] what should happen. What are you willing to do? And, be willing to do that knowing that they will come back again for the next shots versus, I've just lost them." (F)	"[Shared decision-making] addresses the idea of compliance and [tries] to find a way to make it more patient-centered. We would say this patient is compliant, noncompliant and this is a framework to try to understand how the patients are likely to comply or not comply and figure out, are they going to follow our recommendations, do they have reservations? Am I going to give them a recommendation and they're going to come back a year later and they've done nothing with it? Is there a shared model that we can talk about it? It's really getting at that issue, if a physician says, is the patient compliant or noncompliant and how do you address that in that patient and figure out who is and not and why? What can you do about it to help them with whatever issue they bring to the table?" (M)

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# Table 4

Representative quotes from general pediatric and pediatric urology providers about the barriers to implementation of shared decision-making.

	General pediatric providers	Pediatric urology providers
Desire for patemalism	"I use shared decision making to such an extent that every now and again, I get pushback. They're like, "I don't know. You're the doctor. Tell me." I get that. You can definitely do it to such an extent-there are certain families that really want to either be told or to be swayed one way or the other". (F)	"I think shared decision making in a surgical subspecialty as esoteric as ours we come in with a lot of power with our decision and what we know, what people don't know. Parents really look at almost what we say, what we think is what the answer is even if we're trying to make it in a more shared fashion. But, we are much more looked at as experts in this very small subset of surgery that we do." (M)
Misconceptions about medical evidence	"I think [shared decision-making] works much better when families are informed and are savvy and know exactly what is going on. If is a lot harder when there is a true misconception and trying to get through that is just really difficult. So, I find that [at] those times it is not as easy to do. When they really have done their research and they kind of know the sides and they want my opinion [then we can] have that discussion." (F)	"The other thing is regulating the information [the parents] get. What's your source of information and what's the validity of that, really has been one of our struggles but, how you do that is really tricky today because there is no expert that's going to be Dr. Google, right? Everybody is going to want that because that's power. Information is always power, especially in the surgical field because that's how you collect patients. So, it's really hard to control that side of it today." (M)
Decision-making already completed	"If families come to the interaction with a pretty strong feeling and they only want a sprinkle of your opinion that doesn't feel [like] shared decision making to me. I really enjoy shared decision making a lot but I feel like if both of us come from a fairly unbiased position, it's a lot easier to have it be a successful interaction." (F)	"A lot of the time the reason [people are] here is because they already have a plan. They're looking for someone who's going to be able to give them a little bit more information and deliver on this plan for them even with these controversial procedures." (M)
Provider bias/lack of interest	"It's often difficult for us to do [patient counseling] unbiased. Meaning I may talk to them about ADD and the options and I'm going to say, "You need medication." So, I think I probably come with a bias in that. You know, in seeing great response and knowing how things have happened in the past, it's I think sometimes difficult to do unbiased." (M)	"I think there's been a huge shift in medicine to where parents want to be more involved into decision making to the days of when you walked in the room and you were the power in the room and you said, "This is what needs to be done" and they said, "Yes, let's do that." Whereas now they want to feel more rapport and have input and whether you want it or not, it's more shared decision making." (M)