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Parents' Perspectives on Communication and Shared Decision-Making for Febrile Infants ≤60 Days Old

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Abstract

Objectives: Decisions about the management of febrile infants ≤60 days old may be well-suited for shared decision-making (SDM). Our objectives were to learn about parents' experiences with receiving and understanding information in the emergency department (ED) and their perspectives on SDM, including for decisions about lumbar puncture (LP).

Methods: We conducted semi-structured interviews with 23 parents of febrile infants ≤60 days old evaluated in the pediatric ED at an urban, academic medical center. Interviews assessed parents' experiences in the ED and their perspectives on communication and SDM. Two investigators coded the interview transcripts, refined codes, and identified themes using the constant comparative method.

Results: Parents' unmet need for information negatively impacted parents' understanding, stress, and trust in the physician. Themes for parents' perspectives on SDM included: 1) giving parents the opportunity to express their opinions and concerns builds confidence in the decision-making process; 2) parents' preferences for participation in decision-making vary considerably; and 3) different perceptions about risks influence parents' preferences about having their infant undergo an LP. While some parents would defer decision-making to the physician, they still wanted to be able to express their opinions. Other parents wanted to have the final say in decision-making. Parents valued risks and benefits of having their child undergo an LP differently, which influenced their preferences.

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Conclusions: Physicians need to adequately inform parents to facilitate parents' understanding of information and gain their trust. SDM may be warranted for decisions about whether to perform an LP, though parents' preferences for participating in decision-making vary.

Keywords

neonate; parent; shared decision-making; risk; meningitis

INTRODUCTION

Each year in the United States, over 400,000 infants ≤60 days of age are evaluated for fever in either an emergency department (ED) or a primary care office.[1] Although most of these febrile infants will have self-resolving viral infections,[2] approximately 10% will have a serious bacterial infection, nearly 1% of which will be bacterial meningitis.[1,3] Various criteria are used to stratify febrile infants by their risk of serious bacterial infection. While well-appearing febrile infants 29 to 60 days of age with normal urine and blood test results have a low risk of meningitis,[1,4,5] the precise frequency of meningitis in these "low-risk" infants is unknown.[6] In deciding whether to perform a lumbar puncture (LP) on these infants, emergency medicine clinicians must weigh the risks of bacterial meningitis, including neurologic sequelae or death,[7] against the risks of the LP, which include the possibility of an unsuccessful painful procedure, stress for parents, and rare serious complications.[8,9] There is wide variation in the frequency with which these infants undergo an LP due to differences in both institutional norms and individual physician's tolerance for risk.[10,11]

When the harm/benefit ratio of a decision is unclear, parents' values and preferences should be incorporated through a shared decision-making (SDM) approach.[12] SDM requires that parents understand the trade-offs inherent among the options available. The physician then helps the parents both consider and articulate what is important to them in making the decision (i.e., their values and their preferences).[13] Although decisions regarding the management of febrile infants have been identified as well-suited for SDM,[14] emergency medicine physicians and nurses have both identified several barriers to SDM with parents of febrile infants, including parents' emotions and the difficulty of effectively communicating complex information.[11] However, parents' preferences for their involvement in making decisions about their febrile infant have not been explored. Our objectives were to learn about parents': 1) experiences with receiving and understanding information, including the options available to them (i.e., whether or not to have their infant undergo an LP) and the risks/benefits related to LP, and 2) perspectives on SDM for decisions for their infant, and specifically for the decision about whether their infant should undergo an LP.

MATERIALS AND METHODS

Study Population and Recruitment

The study was conducted at urban academic medical center that includes a tertiary-care pediatric ED. We conducted one-on-one, semi-structured interviews with parents of infants ≤60 days of age with at least one rectal temperature ≥38.0° C (100.4° F) in the ED, at

home, or in an outpatient clinic. Parents were eligible for inclusion if their infant either was evaluated in the pediatric ED or was hospitalized at the medical center after evaluation at an affiliated general ED. Pediatric emergency medicine fellows and attending physicians were informed through email that the principal investigator would be conducting interviews with parents of febrile infants to learn about parents' experiences and perspectives on communication and decision-making. The study was approved by the institutional review board and written informed consent was obtained. A small monetary incentive was provided to parents for participating.

The principal investigator identified potentially eligible parents through notification from the clinical team in the ED and through daily query of the electronic health records for hospitalized infants. Eligible parents were approached for enrollment in the ED or on the inpatient floor. Enrollment occurred during both weekdays and weekends, including evening hours. Purposive sampling was used to ensure inclusion of parents of infants ≤28 days and 29 to 60 days of age, and of infants who underwent an LP and those who did not. Parents of hospitalized infants were interviewed in their hospital room within 24–48 hours of admission, with the exception of one parent who was interviewed by phone 96 hours after hospital discharge. Parents whose infants were discharged from the ED were interviewed by phone within 24–48 hours of the ED visit, with the exception of one parent who was interviewed at 96 hours.

Interviews

Semi-structured interviews were conducted between October 2018 and February 2019 by a pediatric emergency medicine attending physician trained in qualitative interviewing. The interviewer identified himself as a physician but was not involved in the care of the infant. The semi-structured interview guide included open-ended questions about parents' experiences with receiving and understanding information in the ED, and about their perspectives on communication and SDM, including their preferences for additional information to augment verbal communication with providers. Prompts were used to encourage parents to elaborate and to clarify responses.[15] Interviews were audio-recorded and transcribed verbatim by a professional transcription service. Prior to the interview, each parent completed a form that included the parent's age, gender, race/ethnicity, number of children, highest education level, health literacy (by asking, how confident are you in completing medical forms by yourself, with answers "somewhat," "a little bit," or "not at all" defined as limited health literacy),[16,17] and preferences for participating in healthcare decisions for their infants using the Control Preferences Scale.[18] If more than one parent was present for the interview, a form was completed by each parent.

Data Analysis

Two investigators met weekly to review transcripts and to iteratively revise the interview guide. The interview guide was finalized after four interviews and is shown in Supplemental Table 1. We used inductive analysis to identify themes related to parents' understanding and their perspectices on SDM. We used deductive analysis to describe parents' preferences for additional communication methods. The two investigators developed an initial codebook and independently applied codes to the data using the constant comparative method.[19,20]

They met weekly to compare codes and to resolve discrepancies, and the coding guide was iteratively revised as needed. Each transcript was re-coded using the final version of the coding guide. To demonstrate triangulation, the final version of the coding guide was sent to a third investigator who applied the codes to a selected transcript, the results of which were concordant with those of the other investigators. The coded data were grouped into salient categories by topic, and both meaning and themes were identified. Thematic saturation[19,20] was achieved after interviews with parents of 20 infants. ATLAS.ti (version 8) was used for data management.

RESULTS

We approached 26 parents of whom 23 (parents of 20 infants) agreed to participate. Characteristics of parents and their infants are listed in Table 1. The majority of parents were mothers, 55% had a highest education level of high school (or equivalent) degree or no degree, and 35% had limited health literacy. Overall, 65% of parents reported that they preferred to make the final decision about testing or treatment for their baby either independently or after seriously considering the physician's opinion. Among infants of enrolled parents, 75% were hospitalized and 65% underwent an LP. Interviews lasted a median of 21 minutes (range 14 to 40 minutes).

Parents' Experiences with Receiving and Understanding Information

Review of the transcripts revealed that parents' need for information, whether unmet or addressed, was an important influence on their understanding, emotions (specifically level of stress and anxiety), and trust in the physician (Table 2).

Need for Information Not Met—Some parents felt too overwhelmed to formulate questions, which led to unmet information needs. One mother, whose 7-week old infant underwent an LP, did not understand what was happening and found it difficult to know what questions to ask:

> "It was kind of difficult because I didn't know exactly what was going on and what they were doing, so it's like, what do I ask? What are they doing? Should I say this? Should I say that? It was kind of hard for me to even approach."

She did not describe being prompted to ask any questions or whether any of the clinicians confirmed her understanding of what procedures were either being performed or considered for her infant. Other parents highlighted the need for additional information as the situation evolved, particularly for invasive procedures. One father of a 6-week old infant said:

> "….they spent probably cumulative of a half hour to 45 minutes trying to get the blood out from him and get a good stick in him. So at that point I would've liked to have known….I understand there is a concern of bacterial infection, but we didn't know what the likelihood of that would be. So it doesn't make sense to continue trying and continue failing….or is there a better option here? Like, does it make sense to just monitor him or keep an eye on the temperature or do something besides, you know, four more failed attempts at getting blood?"

For some parents, unmet need for information also increased stress and anxiety. For the mother of the 7-week old infant, not knowing the risks of an LP made her feel scared:

> "*Is he going to be okay? Is he going to be physically okay? Is he going to be a vegetable?* Like stuff that is scary. And I feel like they should inform me a little bit more on what they are going to do….I feel like they were answering in a type of way where they didn't want to say too much. That's how I feel, and it's scary."

For other parents, the unmet need for information and the concomitant anxiety occurred at disposition from the ED. One mother whose 4-week old infant was discharged from the ED said:

> "The discharge was kind of, to me, shaky. Because I expected the doctors to come back and just circle back with any information….it would've been neat to come back and just report that okay, you're okay, you're clear to go home….there was no discussion. I guess there was no problem….the discharge was messy to me. It gave me anxiety."

While most parents trusted the physicians' decision-making, one father of a 2-week old infant described how being insufficiently informed led him to distrust the physician. This distrust influenced the father's decision to refuse an LP:

> "The more information the better….I want to know everything that's going on with my son….The less information we know, the more distrust we feel. We don't know if the doctor's going in there and doing who knows what. Just because he's a doctor doesn't mean I should trust him. He needs to give me information on what are the risks - that needs to be much more open because I automatically did not trust him when he told me he wanted to bend my baby in a ball and stick something in his spine….So if they give you more information, that would be much more helpful."

Need for Information Met—In contrast to the mother who felt too overwhelmed to know what questions to ask, some parents who wanted information proactively sought to obtain it. One mother with limited health literacy, whose 6-week old infant had an LP, asked the physician to use language that she could understand:

> "I'm not a doctor, so the language they give you, the way they're speaking the language, these big words and stuff and I just ask them to break it down to me to where I can understand what he's talking about and he did that. So that was pretty nice….he broke it down to me to where I could understand what he was talking about and that was about it."

Some parents felt that being informed helped them feel less anxious about their infant's care. A mother of an 8-week old infant who was discharged from the ED without an LP said:

> "I think it really lowered my anxiety about just having him home and the severity of what he was going through and if he displayed certain symptoms, what to do. So I felt more informed and therefore less anxious about getting him well at home."

A mother of a 7-week old infant indicated that her anxiety was reduced when the physicians and nurses proactively addressed her needs:

> "I mean, I get that this is hard to see your baby in pain and uncomfortable so if they seem sympathetic to that, I think that's important. And everybody was very like, oh, do you need anything? Can I get you anything? So I think those two things are the most important. Ask if you need something or what can I do to help you?"

Some parents expressed that feeling informed gave them confidence in the plan of care. One mother of a 2-week old infant said:

> "I was pretty reassured because they told me once what they were going to do. They gave me a total outlook of what they were going to do and then specifically when they came in to do things they explained it again. I was confident."

Other parents felt that when a physician showed them the results of research, it helped their understanding and gave them more trust in the physician. One mother of a 4-week old infant said:

> "When you listen to a doctor, although you trust the doctors, he's explaining everything right, but if he shows us a study or something like that, it adds our trust. It adds more trust."

Parents identified several approaches to address parents' information needs, including having expectations set by the primary care pediatrician about what would happen in the ED and periodic reinforcement of the plan by the physicians (please see Table 3 for representative quotations). Providing parents with an information sheet was also identified as a method to improve communication. One mother felt confident in her 4-week old infant undergoing an LP when the physicians provided her with an information sheet on risks:

> "They gave me a fact sheet, like a CDC type report of how things measure up. So they gave me percentages of risk as well as how many people they have performed it on….So for me, that builds confidence."

Some parents felt that having information on either paper or an electronic device would be useful for parents who wanted to learn more through reading. One mother of a 3-week old infant said:

> "….some people understand better by reading it than just hearing it. Some people understand better by hearing it than reading it, so I mean, it could work both ways. It depends on what type of person it is."

Parents' Perspectives on Shared Decision-Making

Three themes emerged about parents' perspectives on SDM in the care of the infant (Table 2). First, giving parents the opportunity to express their opinions and concerns builds their confidence in the decision-making process. Second, parents' preferences for participating with the physician in decision-making vary considerably. Third, for the specific decision about whether their infant should undergo an LP, parents have different perceptions about risks that influence their preferences for LP.

Opportunities for Parents to Express Opinions/Concerns Builds Their Confidence—Parents' feeling listened to was linked to their trust of the physicians in making decisions for their infant. One mother of a 5-week old infant said:

> "I feel that it's important for the doctors to listen to you even if you don't have a lot of experience in the field or what's going on. I think as a scared parent, it helps you have a little more confidence with the people who are treating your child or yourself."

A mother of a 2-week old infant similarly expressed that she would have more confidence in the decisions if her opinions were taken into consideration:

> "I mean I know I didn't go to school for however long they did, but it's my son, so you know, I would feel confident and better if I did have a say, so in whatever goes on with his little body."

Addresing parents' concerns about LP also built trust. One mother of a 4-week old infant said:

> "They were really helpful because when they would explain it to us, they would take out some fluid from the spine, so we were not sure or we were concerned that there would be some numbness on the back area, or if they take out some fluid, how much time the body takes to develop the fluid, so all those questions were answered by the doctors correctly. It was trustful for us."

Parents' Preferences for Participation in Decision-Making Vary—Parents expressed different preferences for their actual involvement in decision-making (please see Table 4 for representative quotations). Some parents said that they would generally defer decision-making to the physician, but they needed to understand the rationale to be comfortable with the decision. One mother of a 7-week old infant said:

> "I mean, my perspective …. you're the expert. You tell us what we need to do and make sure we understand it and we're comfortable with whatever it is. If we're not comfortable with something, I would want the doctor to listen to that and maybe they can find a different way to do it that we would be comfortable with, but at the same time, we understand that you're the expert in this and this is your job. I think we would defer to that."

Some parents preferred to defer most decision-making to the physicians except in certain circumstances. A mother who was a physician, and who consented to have her 5-week old infant undergo an LP, said:

> "I mean, I think I want to be involved, but also I respect the people who do it all the time and know pediatrics….I don't have much experience with very sick kids, so I trust their opinion. But at the same time, if I felt very strongly that we were doing something we didn't need to do, then I'd probably put my foot down."

Other parents said that they would defer decision-making entirely to the physicians, if they felt that either the test or the treatment would benefit their infants. One father of a 3-week old infant said:

> "I'm not a doctor or anything. I trust the doctor's opinion and if he says that he wants to perform some type of test, if it's going to help him, then I'm all for it."

A few parents felt that they should have the final say in decision-making, if the providers' adequately explained their recommendations so that parents could understand. One mother who was a nurse said:

> "….coming from a nurse's perspective, it's kind of a little bit annoying when family members come in and they just refuse something without totally understanding why it's necessary, but also that's our job to explain it. The doctors and the nurses, obviously. I mean, I think when it comes down to it, the parent always should have the final say, regardless of – I don't know, when it's a life-threatening thing, I guess they still do have the final say, but it's whether the doctor is good enough at convincing them. Or providing information I should say."

One mother of a 4-week old infant stated that it was vital for parents to be involved in decision-making if that was their choice:

> "I think that's a vital part of the care is involving the parents if the parents choose to be involved. They know exactly what's going on with their child."

Risk Perceptions and Preferences for LP—Some parents felt that any risk of meningitis was too high to not have their child undergo an LP. The mother who was a physician said:

> "I mean, it's a scary thing. I stick needles in people's backs all the time, so I shouldn't be that upset about them doing it to one of my own people. But meningitis is a pretty scary thing in a baby, so it's better to know even though the likelihood is low, you don't want to miss it."

One mother of a 6-week old infant described how information helped correct her misperceptions about the risks of an LP:

> "Just hearing the word "spine" just scares me because I don't know, maybe he would get paralyzed or whatever. After the doctor came in and explained everything to me, I definitely did feel more assured that I wasn't making the wrong decision. Just them telling me the risks and paralysis was not even one of them."

Another mother was more comfortable having her 4-week old infant undergo an LP once she had a better understanding of the risks and benefits of the procedure. Referring to an LP as a frequently performed procedure lessened her concerns:

> "They explained that….It's a very developed sterilization process and how they mitigate that risk. And then talked about her track record of, okay, if you've done maybe four or five already in that day and children of the same age groups, so this is not something that is – as I was thinking, a rare thing that they have to do. This is something that they do very frequently and that they're proficient at doing it. It may cause discomfort for the baby, but the risks and the benefit of finding out if she has a serious infection is better than the discomfort that she might feel for just a short amount of time."

In contrast, the mother who was a nurse felt strongly that an LP was not necessary because she felt there was an alternative explanation for her infant's fever:

> "I know meningitis is a big deal….I get that they're trying to rule all of the big things out….I knew we were all sick at home, I was like, 99.9 percent sure it wasn't meningitis. So I really was against it and then every doctor that came up was trying to convince me to do it just for peace of mind. Like, I get it, but I just didn't want to. He had already been stuck multiple times for the IV. I said I don't want to torture him….He kept saying we do it all the time on kids – regardless of that, it's still an invasive procedure and it's something that I didn't want."

One mother, whose 5-week old infant underwent an LP, described how her anticipation of feeling regret influenced her decision:

> "I'm not a physician. I don't know fully what's best medically for her. So do I think the odds of her having meningitis are super low? Sure. Would I ever be able to forgive myself if she had meningitis and I chose not to do a spinal tap? …."

DISCUSSION

Parents of febrile infants ≤60 days of age have specific information needs, that if not addressed, affect their ability to accept the rationale for proposed interventions, increase both their stress and their anxiety, and may result in distrust of the emergency medicine physician. All of these effects can negatively impact parents' ability to participate in the decision-making process. While parents of febrile infants have different preferences for their actual participation in decision-making, they felt that it was important to have the opportunity to express their opinions. When parents are presented with an option to participate in the decision of whether to perform an LP, they value the potential risks and benefits differently, thus underscoring the importance of implementing an SDM approach for this decision.

For decisions in which the risk/benefit ratio of the options are unclear, a SDM approach is recommended.[12] About half of febrile infants evaluated in the ED will be classified as "not low risk" by various algorithms used in clinical practice.[1,2,4] For many emergency medicine physicians, the risk/benefit ratio favors performance of LP for these infants and SDM may not be appropriate.[10] However, as we learned from parents, it is still important for physicians to explain the reasoning behind the decision and to give parents the opportunity to express their concerns, opinions, and feelings. As parents vary in their comfort and ability to ask questions, physicians and nurses should proactively elicit parents' concerns throughout the ED visit. Additionally, our results demonstrate that ineffective communication may lead to distrust, potentially resulting in refusal to consent for an LP.

For febrile infants classified as "low-risk," as well as for infants with an abnormal urinalysis who are otherwise "low-risk," there is a low but uncertain risk of bacterial meningitis.[1,4–6,21] An SDM approach would be appropriate for these infants. We learned from parents that once they felt informed and had the opportunity to ask questions, some will defer decision-making to the physician. However, given their different preferences, all parents of "low-risk" infants should still be presented with the options about whether their child should undergo

an LP and they should be invited to participate in decision-making. To participate in SDM, parents need to understand information about both the risks and the benefits of the options.[13] Physicians and nurses have identified both parents' understanding and their emotions as barriers to SDM for febrile infants.[11] We learned from parents that their understanding and emotions are linked, as unmet need for information negatively impacted their understanding of information and increased both their stress and their anxiety. The effect of unmet need for information on parents' emotions may impair their ability to pay attention to information on risks during decision-making about LP.[22] Adequately addressing parents' need for information can overcome this barrier to SDM.

However, there is limited research on SDM with parents of acutely ill children in the ED.[23,24] A recent multicenter trial of SDM vs. usual care for the decision of whether to have children with head trauma undergo computed tomography of the brain found that parents' knowledge, trust of the physician, and involvement in decision-making were higher with use of SDM.[25] Our study is the first to assess parents' preferences for for participation in decision-making for febrile infants. Future research should explore how best to implement SDM with parents of febrile infants as well as the effect of SDM on outcomes such as decision-making quality and rates of LP.

Our study has several limitations. First, the perspectives of parents in our study may not be generalizable to parents in other EDs, in particular general EDs or those outside the U.S. However, we interviewed parents from a range of socio-demographic backgrounds, including parents of limited health literacy. We also included the perspectives of parents whose infants underwent an LP and of those whose infants were discharged from the ED without an LP. Second, interviews were conducted by a pediatric emergency medicine physician, which may have influenced parents' responses. Third, while we obtained rich narratives from parents about their perspectives on participation in decision-making, we did not assess their actual involvement in making decisions for their infants. Fourth, we did not interview any parents whose infants had bacteremia or bacterial meningitis, and future investigation is needed to learn the perspectives of infants with more serious illness.

CONCLUSIONS

Addressing parents' need for information can facilitate parents' understanding about the care of their febrile infant and gain their trust, both of which are necessary for parents to be able to participate in the decision-making process. For parents of "low-risk" infants, SDM may be warranted for the decision of whether to perform an LP, though the process should be individualized, as preferences of parents for participating in decision-making vary.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Characteristics of Parents and Infants

Characteristic	N (%)
Parents, n=20 [1]	
Gender	
Female	17 (85%)
Male	3 (15%)
Age, median (IQR)	28.5 (24–34)
Number of Children, median (IQR)	2 (1–3)
Race/Ethnicity	
White	10 (50%)
Black	3 (15%)
Hispanic	4 (20%)
Asian	1 (5%)
>1 Race/Ethnicity[2]	2 (10%)
Highest Education Degree Obtained	
GED	2 (10%)
High School[3]	8 (40%)
College	4 (20%)
Graduate	5 (25%)
No degree	1 (5%)
Limited Health Literacy[4]	7 (35%)
Preferences for Making Healthcare Decisions for the Infant	
Prefer to Make Final Testing/Treatment Decision	2 (10%)
Prefer to Make Final Testing/Treatment Decision After Seriously Considering Doctor's Opinion	11 (55%)
Prefer to Share Responsibility with the Doctor for Testing/Treatment Decision	5 (25%)
Prefer that Doctor Makes Final Testing/Treatment Decision After Seriously Considering My Opinion	1 (5%)
Prefer to Leave All Testing and Treatment Decisions to the Doctor	1 (5%)
Infants, n=20	
Age Group	
≤28 days	6 (30%)
29–60 days	14 (70%)
Underwent Lumbar Puncture	13 (65%)
Hospitalized on Initial ED visit	15 (75%)
Serious Bacterial Infection[3]	3 (15%)

[1] Three interviews included input from both parents; characteristics provided for the parent who predominantly participated in the interview

[2] One parent identified as "Mixed Race" and 1 parent identified as Hispanic and White

[3] One parent completed high school and was currently completing college

[4]Defined as answering “somewhat,” “a little bit,” or “not at all” to the question, “how confident are you in completing medical forms by yourself?”

[5]Three infants had a urinary tract infection; no infants had bacteremia or bacterial meningitis

Abbreviations: ED, emergency department; GED, General Education Diploma; IQR, interquartile range

Table 2.

Themes and Sub-Themes

Parents' Experiences with Receiving and Understanding Information	
Theme #1	Need for Information Unmet or Met
Sub-Theme i	Parents' Understanding
Sub-Theme ii	Parents' Emotions
Sub-Theme iii	Parents' Trust
Parents' Perspectives on Shared Decision-Making	
Theme #1	Giving parents the opportunity to express their opinions and concerns builds their confidence in the decision-making process
Theme #2	Parents' preferences for participating with the physician in decision-making vary considerably
Theme #2	Parents have different perceptions about risks that influence their preferences for LP

Table 3.

Facilitators of Addressing Parents' Need for Information

Category	Representative Quotations
Prior Knowledge	
Mother who was previously a nursing student and whose infant had an LP during a prior hospitalization	"I did, but I understood the risks and the possible side effects before we even went to the hospital and that's, again, because of my background. So I don't – I can't quite speak for other parents if they felt as comfortable making that kind of decision at that moment in the hospital where I – okay, I know what a spinal tap is, I know what the possible side effects are, but my daughter needs it, so this is what I have to do. I can't quite say I would have so calmly understood the side effects or consequences or procedure as the doctors explained it in that moment if I wasn't already previously aware."
Primary Care Pediatrician	
Mother of a 4-week old infant who underwent an LP	"So I called the pediatrician-clinic and left a message and then she called me back within five minutes, which is great. I told her the temperature and she knew the age of the baby, so with her being a month, she's like, okay, so I'm going to need you to go to Yale. She actually did prepare me for what actually did happen, which was great because babies don't come with a manual and I wouldn't have even – I wasn't sure if she was like, hey, bring her in to the office, but she said, nope, you're going to go right to Yale. She's like, just to give you a heads up, there will be blood work taken, she may need a spinal tap. So I was warned of that on that initial phone call, which was great."
Repetition of Information	
Mother who is a nurse and whose husband is not in the medical field	"I think things are constantly changing in that situation, like they have a plan, but the plan always changes based off what's happening at the time. But yeah, bits and pieces I think might be more helpful because if it's too much all at once, like, you miss things or you forget things. I even noticed like, in a situation like that, my husband would be like, oh, they said this. And I'm like, oh yeah, you're right. I missed that. Just because it's a lot and when you're a parent and especially if you don't know – if you don't have a medical background, like, you are clueless and you're worried. So it's like, the more reinforcement I think the better."
Information Sheet	
Mother of a 1-week old infant who underwent an LP	"I think for parents who don't have a medical background or haven't had to go through this before, it's a very quick process and to be able to take any information of how the procedure is done, the possible side effects, why the procedure is done, it's kind of hard for parents to take all of that information in when they really just want to hold their baby and comfort their baby and just know what's wrong. So it's a lot of information, it's a lot of faces, it's a lot of people in and out of the room. It's definitely a very scary experience, especially with a child so young. So I think an information sheet, whether they had time to read it or took the time to read it right then and there, I think it would be beneficial for – I mean, the doctors already did a wonderful job explaining it and asking if you have any questions, but I think after the fact, it's probably nice to have a piece of paper to review just to – what did the doctor say was a possible side effect? What do we need to look out for again? I think that would absolutely be beneficial for some parents."

Table 4.

Parents' Preferences for Participation in Shared Decision-Making

Theme	Representative Quotations
Preference to have the physician make the decision	
Mother of a 4-week old infant who underwent an LP	"…. I trust the doctor. That's why I came to the hospital. So I think I just let him do – I think they know what they are doing, so I trust them."
Preference to have the physician make the decision once the parents are informed	
Mother of a 3-week old infant who underwent an LP	"I'm pretty forthcoming when it's something that I feel like I have enough understanding of. Again, I'm not a doctor. I respect that you have far more training and experience than I do. But I like to understand the reasoning of things and the pros and cons and why we're making whatever decisions we're making."
Mother and father of a 3-week old infant who underwent LP	"At the end, I'm still going to listen and allow them to do what they have to do….I feel as though as long as they're breaking it down as they go along, that's, I don't know….enough for me….Keep me posted. I don't even have to ask questions if you're already answering them for me as you're going along….Let them do their job. You don't want to get in their way too much, you know? You don't want to stop them or slow them down. Just go ahead, do your thing."
Preference to defer decision-making to the physician except under certain circumstances	
Father of a 6-week old infant who did not have an LP and was discharged from the ED	"Well, I think that – I've said it before, but I think the doctors obviously know a lot more about this stuff than I do, so if they were coming with the recommendation, there's a 99 percent chance I would follow it. Again, the only time I would say let's do this or let's not do that would be if they were checking for something that the test was like, so invasive or painful. Or even financially crazy, right? It's like such an expensive test that we'd end up having to pay for, where the chances of finding something was so slim that in our – it wouldn't be worth it. But other than that, I feel like the decision would primarily be the doctor's and we would just want to be informed on what their decision is and why."
Preference to make the final decision	
Mother who felt that she and her husband made the decision about an LP for their 1-week old infant after listening to the physician's opinion	"Um, I would say for all decisions. I mean, we absolutely take the doctor's opinion into consideration, but at the end of the day, we'd like to be the ones who make the final decision on what our daughter goes through, what kind of treatments, what kind of procedures. But definitely – we definitely would take the opinions of the doctors and the specialists into consideration."