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# Primary Care Providers' Experiences Notifying Parents of Cystic Fibrosis Newborn Screening Results

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## Abstract

This study examines primary care provider (PCP) experiences with the initial parental disclosure of cystic fibrosis (CF) newborn screening (NBS) results in order to identify methods to improve parent-provider communication during the CF NBS process. PCPs of infants who received positive CF NBS results participated in semistructured phone interviews. Interviews were analyzed using a qualitative content analysis. PCPs acknowledged the difficulty of "breaking bad news" to parents, and emphasized minimizing parental anxiety and maximizing parental understanding. PCPs used a variety of methods to notify parents, and shared varying information about the significance of the results. Variation in the method of parental notification, information discussed, and attention to parents' emotional needs may limit successful follow-up of children with positive CF NBS results. A multifaceted intervention to improve PCP knowledge, management, and communication could improve provider confidence, optimize information transfer, and minimize parental distress during the initial disclosure of CF NBS results.

## Keywords

newborn screening; cystic fibrosis; communication

## Introduction

Newborn screening (NBS) for cystic fibrosis (CF) aims to identify newborns with CF and initiate treatment before symptoms arise. In the United States, NBS begins with an initial blood test at birth and those infants with a positive screening result for CF require additional follow-up testing to determine whether they have the disease.[1] The child's primary care provider (PCP) is responsible for notifying parents of the infant's initial NBS result and for arranging the appropriate follow-up testing.[2] Communication during this notification process can be challenging for both the PCP and the parent for a number of reasons. First, it

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The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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requires PCPs to have sufficient knowledge about NBS for CF to explain the screening result to parents and to advise them on the next steps in the evaluation of their child. Second, PCPs must be sensitive to the fact that parents may be shocked and anxious after learning of their child's positive CF NBS result,[3,4] emotions that can interfere with parental processing of information and lead to misunderstandings of the child's health status.[5,6] Previous studies have shown that PCPs lack confidence in discussing and managing positive CF NBS results,[7] and that physicians' communication may be hampered by use of jargon and lack of open-ended probing about parents' emotional status.[8–10]

Successful communication practices, particularly regarding initial positive NBS results are imperative for the long-term success of NBS programs, establishment of public trust, and positive family outcomes. Despite the extent and long history of these important programs, it is unknown how best to communicate positive results to parents in order to assure the provision of accurate information, to foster a prompt response, and to reduce the risk of excessive anxiety following positive results. Negative consequences from positive NBS results may be minimized through improved communication between the provider and parent, and research supports the notion that providers want and need help with communicating positive NBS results to parents.[8,11–14]

The concern over communication of positive results was recently highlighted by the US Preventive Services Task Force, which concluded that research is needed to identify plans that can improve communication practices.[15] Given that PCPs are responsible for disclosing initial positive CF NBS results to parents, their perspectives are critical to any attempts to assess and improve this communication process. Therefore, we conducted semistructured interviews with PCPs who have communicated with parents about positive CF NBS results to investigate their experiences with the initial disclosure and to identify areas for improvement in this process.

## Methods

This qualitative content analysis utilized semistructured phone interviews to examine the experiences of PCPs who informed parents of their child's positive CF NBS result. This study was approved by the institutional review boards at the University of Michigan and the Michigan Department of Community Health (MDCH).

### Population

Providers were eligible for participation if they practiced in Michigan, were the PCP for an infant who received a positive CF NBS result within the previous 12 months, and communicated with the infant's family about the screening result. To maintain the confidentiality of infants and families who received positive CF NBS results, MDCH identified eligible PCPs and mailed the recruitment documents. After reviewing the recruitment materials, PCPs returned a response card to MDCH indicating their level of interest in participating in the study (yes, no, maybe). MDCH forwarded the contact information of individuals who responded with a "yes" or "maybe" to the research team at the University of Michigan, who then contacted the PCPs and consented those interested in

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participating. PCPs who completed the interview were mailed a $40 gift card for their participation.

### Interview Script

The phone interviews lasted 20 to 35 minutes and followed a semistructured interview script. The script contained open-ended questions that asked PCPs to narrate how they were notified of their patient's positive CF NBS result, how they handled the screening result, and how they communicated with parents about the result. Participants were also asked to identify perceived strengths and weaknesses in the notification and communication processes. When necessary, participants were probed to clarify specific details about their experiences (see Table 1 for a list of questions). Each interview was audio recorded, transcribed, and de-identified. Transcripts were verified for accuracy by a member of the research team.

### Data Analysis

A qualitative content analysis, which uses codes to categorize and link similar data, was used to analyze the interview transcripts. After reading the first three transcripts, the study team drafted a set of codes that represented emerging themes. The coding template was systematically applied to all interview transcripts with the option for open coding to capture themes missed with the development of the original coding template. No new codes were generated by the 10th interview, but all transcripts were coded and included in the analysis. The coded data were then moved into matrices based on degree of similarity,[16] and assimilated to form the following categories: Variation in method for contacting parents and information provided, lack of PCP preparation for and comfort with notification process, difficulties associated with being the first point of contact, managing parental anxiety, and PCPs' recommendations for improving the notification process.

## Results

Fifteen PCPs agreed to participate in a phone interview. One participant declined to have the interview audio recorded, which did not allow for a qualitative analysis of the responses. The remaining 14 interviews produced transcripts that were included in the content analysis. Participant characteristics are listed in Table 2. Providers reported communicating with parents about CF NBS results between one and 15 times during their careers (mean = 4.2 times). The time that had elapsed since their most recent discussion regarding positive CF NBS results ranged from 1 month to 11 months (mean = 5.6 months). Eleven of the PCPs' patients were determined to be CF carriers, and three were confirmed to have true positive results. Four participants mentioned that they knew the families prior to notifying them of the CF NBS result, while 10 PCPs did not specify whether they had any relationship with the families beforehand. The themes identified through the content analysis are discussed below.

### Variation in Method for Contacting Parents

Participants described a variety of methods for notifying parents of their child's positive CF NBS result. The majority of PCPs reported that they contacted the families personally and

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informed them of results over the phone. Other methods included scheduling an in-person appointment to discuss the results, asking a nurse or a nurse practitioner to call the family, and waiting to notify parents until the family returned for their next office visit.

### Lack of PCP Preparation for and Comfort With Notification Process

Primary care providers reported a range in their comfort with discussing CF NBS results with parents. Some admitted to feeling “hesitant” about how to proceed, whereas others felt “very comfortable.” No interviewees reported participating in formal preparation prior to delivering the CF NBS results. Some PCPs relied on previous experiences with CF patients or on residency experiences to guide their conversations with parents. Interviewees also accessed other sources when they needed a “refresher” on the meaning of the results and how to coordinate appropriate follow-up. Specifically, PCPs reported referencing the informational sheet the state sends with the NBS results, accessing the MDCH website, calling the CF specialty center, and conducting general internet searches. Representative quotes are listed in Table 3.

### Difficulties Associated With Being First Point of Contact

Primary care providers described many difficulties regarding their responsibility as parents’ first point of contact for a child’s CF NBS results. PCPs expressed that informing parents of their child’s positive CF screening result is challenging and requires managing the results appropriately, determining the content of the initial conversation, and addressing parents’ questions. Representative quotes are listed in Table 4.

**Management of Results—**After notifying parents of their child’s positive CF NBS result, PCPs are responsible for ensuring that the family pursues appropriate follow-up testing. Some participants expressed that they themselves were unsure of the next steps in the CF NBS process and were not always confident when advising parents on how to proceed. Additionally, ensuring that parents pursue proper confirmatory testing was challenging for some physicians, given that some parents delayed this process because of travel concerns, financial concerns, or a misunderstanding of the urgency of the CF NBS result.

**Content of Conversation—**It was challenging for PCPs to determine the content of the initial conversation regarding a child’s CF NBS results. Specifically, many struggled with deciding how much information to tell parents before their child underwent confirmatory testing. Some of the PCPs stated that they only informed parents about the initial NBS positive result, the potential for false positives, and the need for follow-up testing. Other PCPs also provided specific genetic mutation information and in-depth explanations of CF, including symptoms and disease management. Those who shared less information explained that they didn’t want to cause parents unnecessary anxiety by providing in-depth descriptions of the disease if the child was only a carrier. Still, they wanted to share enough information to ensure parents understood the importance of pursuing follow-up testing. In attempt to find an appropriate balance, PCPs identified many factors that they used to determine what information to share during the initial conversation. PCPs stated that the amount of information discussed depended on the patient’s family history related to CF, the

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number of CF mutations found on the newborn screen, the current health of the child, the parent's knowledge of the disease, the parent's education level, and the parent's emotional state during the time of the conversation.

**Addressing Parents' Questions—**In response to parents' questions regarding their child's CF NBS result, PCPs offered a variety of resources that provide additional information. Many PCPs assured parents that they could re-contact the doctor via phone or e-mail if they thought of additional questions. Other options included directing parents to the CF specialist, or providing them with written materials from the American Academy of Pediatrics or the Cystic Fibrosis Foundation. Additionally, some PCPs thought the internet could be a useful resource for parents, whereas others actively discouraged general internet searches until the parents had the confirmatory testing result.

Primary care providers were sensitive to the fact that parents may feel shocked after learning of their child's NBS result, and that this emotional reaction may inhibit a parent's ability to process the information and to formulate questions. To account for the possibility that parents may generate more questions at a later time, PCPs offered many of the same options above such as encouraging parents to recontact the PCP if they think of additional questions, and directing parents to other reliable sources of information.

## Managing Parental Anxiety

Participants were aware that learning of these results had the potential to generate high levels of worry and anxiety among parents. PCPs identified many strategies to address the emotional needs of parents and to help them manage their reactions to this news. Some PCPs assured parents that they would support them through the entire process, and would make themselves available to answer any questions. Many PCPs emphasized that parents cannot be certain of the result until they get follow-up testing, and that the majority of infants with positive CF NBS results are determined to be carriers. Another method was to focus on the current health of the child and emphasize the absence of symptoms. PCPs also assured parents that early detection of CF results in the best health outcomes, and that there are many effective treatments that allow patients to "lead almost normal lives." Representative quotes are listed in Table 5.

## Primary Care Providers' Recommendations for Improving the Notification Process

Primary care providers were asked to identify any perceived weaknesses in the CF NBS process, and to offer their suggestions for improvement. Some physicians expressed that it would be helpful to be informed of the result by more than one method. This would minimize the potential for lost or misplaced fax sheets, and would allow for a more interactive process where PCPs could ask questions about the positive NBS result. Some also suggested that state NBS programs should send an information sheet that PCPs could distribute to parents. This sheet would supplement the initial conversation, and could serve as a reference if parents thought of additional questions at a later time. Physicians also provided some suggestions relating to physician preparation for this conversation with parents. Specifically, some thought it would be beneficial for PCPs to undergo training on how to "break bad news" to patients. Others suggested providing PCPs with a handout that

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listed common questions that parents ask about CF NBS results, and sample responses that PCPs could provide.

Participants strongly emphasized the importance of ensuring that parents thoroughly understood the significance of the NBS result, and shared their methods for improving parental understanding. For example, some physicians found it helpful to present parents with visual aids or written information in addition to providing verbal explanations of the result. PCPs also emphasized the importance of avoiding medical terminology and focusing on the practical implications of a positive screening result in order to avoid confusing parents. Additionally, many emphasized the importance of giving parents the option to ask questions and verifying that parents comprehend the information discussed. Representative quotes are listed in Table 6.

## Discussion

The quality of the conversation during the initial disclosure of a child’s CF NBS result is critical to the successful follow-up and identification of children with positive CF NBS results. This study explored PCPs’ experiences communicating with parents about their children’s positive CF NBS results and identified areas for improvement in this notification process. Our findings suggest that future endeavors to improve the initial disclosure should focus on the following areas: method of communicating positive CF NBS results to parents, content of the initial disclosure, and parental emotional and psychological support.

### Communication Method

Primary care providers reported a wide variety of methods for notifying parents of their child’s positive CF NBS result. Some PCPs informed families of the result in person, some informed them over the phone, and some delegated the responsibility of the initial disclosure to another clinic staff member. Similar findings have been observed in previous studies, where interviews with parents of children with CF NBS results also revealed wide variation in methods of parental notification (B. A. Tarini et al, unpublished data).[17] Because previous research has identified inconsistent information delivery as a weakness in the initial disclosure process,[18] defining a more standardized approach to parental notification may be an important focus for quality improvement in the delivery of CF NBS results.

### Content of the Initial Notification

Physicians who notify parents of their child’s positive CF NBS result must provide clear and accurate information regarding the NBS process, the significance of the positive screening result, and the necessary steps for evaluation of the infant. PCPs in our study shared varying levels of information with parents, and this lack of standardized information transfer raises the concern that some PCPs may have failed to convey these critical points. The issue of conversation content is further complicated by the fact that PCPs were not always confident when communicating about CF NBS, a finding that parallels previous research where PCPs expressed concerns regarding their abilities to deliver these results.[7] There are published guidelines that outline the recommended topics PCPs should discuss with parents during the initial disclosure,[1] and state NBS programs often provide PCPs with handouts that contain

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facts about NBS for CF. However, the extent to which PCPs are aware of and use these resources is unknown. This suggests that additional, more directed interventions (eg, scripts or sample dialogue) may be needed to increase PCP confidence in communicating with parents and to ensure that they accurately communicate information to parents.

### Parental Support

Previous research has demonstrated that PCPs often fail to address parents' emotional states[9] and to ensure that parents understand the necessary information relating to their child's CF NBS result.[19] The PCPs interviewed acknowledged the need to support parents emotionally and described various methods they employed to address parent's emotional reactions. Participants' suggestions for improving this aspect of the communication process included requiring trainings on "how to break bad news" to patients and providing PCPs with sample responses to common questions that parents ask. Currently, most guidance to PCPs regarding the notification process focuses on the transfer of factual information and does not address how to deal with parents' emotional and psychological needs. Therefore, interventions designed to improve PCPs acknowledgement of parents' emotional states may be a fruitful target for future quality improvement initiatives.

### Limitations

Some limitations to our study should be noted. First, this was a qualitative study based on semistructured interviews. As with many qualitative studies, the findings are based on a small study sample and cannot be generalized to all PCPs. However, the goal of qualitative studies is to generate hypotheses in order to provide ideas for future investigations. Additionally, this study only included PCPs who practice in the state of Michigan. While we reached thematic saturation in our sample, it is possible physicians practicing in states that follow a different protocol for the follow-up of CF NBS results may offer additional perspectives. Finally, we only collected data from the PCPs' perspectives of the conversation, and therefore are not sure how the parents perceived the discussion surrounding the initial disclosure. As a result, further research is needed to establish which communication practices are preferred by parents.

## Conclusion

Because parent–provider communication regarding NBS results can have lasting health implications for parents,[3–5] it is important that PCPs effectively manage the initial disclosure of these results. Previous research demonstrates that interventions targeting PCP delivery of CF NBS results decrease time to the infant's sweat test[15] and improve parent satisfaction with the CF NBS process.[20] Thus, intervening with physicians is a realistic option improves the efficacy and quality of the CF NBS process. This study suggests that strategies for improvement might include a multifaceted intervention focusing on physician confidence with the communication process, fidelity of information transfer, and skills for addressing parents' psychological and emotional needs. Such an intervention might facilitate optimal communication between providers and parents, and, in turn, minimize parents' stress and maximize infants' health outcomes.

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## Table 1

Interview Questions Grouped by Topic Area.

- Questions about PCP notification of patient’s CF NBS result
  - How did you first find out about your patient’s positive NBS result for CF?
    - How were you contacted?
    - Who contacted you?
    - What information was provided to you?
  - Was there anything about this process you wish would have been done differently?
- Questions about communication with the family
  - Who notified the family in this particular case?
  - How did you notify the family of their child’s CF NBS result? (phone, in person, etc)
  - How well prepared did you feel to notify the parents?
  - What did you tell the family in relation to their child’s positive CF NBS result?
  - What was the parent’s reaction?
  - What did you do to help parents manage their emotional reactions?
  - How well do you think parents understood what you told them?
- General questions about screening for CF
  - What do you feel is your role in the notification process for a positive CF NBS result?
  - What information about cystic fibrosis is important to convey during the initial contact?
- Questions about the evaluation of the infant
  - How involved were you in the child’s workup for the positive NBS result?
  - How involved were you in the process of explaining the results of the workup to the parents?
  - How well do you think they understood the meaning of the sweat testing result?
- Perceptions of CF NBS process
  - What aspects of the parent notification process for CF NBS went well?
  - What are some areas for improvement in the notification process for CF NBS results?

Abbreviations: PCP, primary care provider; CF, cystic fibrosis; NBS, newborn screening.

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## Table 2

Characteristics of Interview Participants (N = 14).

| Characteristics | n | Percentage |
|---|---|---|
| Gender | | |
| Female | 5 | 36 |
| Male | 9 | 64 |
| Age (years) | | |
| 30–45 | 5 | 36 |
| 45–60 | 4 | 28 |
| >61 | 5 | 36 |
| Training | | |
| Pediatrics | 11 | 79 |
| Family medicine | 1 | 7 |
| Med/Peds | 1 | 7 |
| Nurse practitioner | 1 | 7 |
| Practice setting | | |
| Private practice | 8 | 57 |
| University | 3 | 21 |
| Community health clinic | 3 | 21 |

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## Table 3

Illustrative Quotations: Lack of PCP Preparation for and Comfort With Notification Process.

| |
|---|
| Variation in how comfortable PCPs feel |
| Uncomfortable with process |
| This being my first time going through this process, I was slightly hesitant that I didn’t know exactly what to do. |
| Comfortable with process |
| I trained in [city], I was in the tertiary care facility there and saw tons of patients with cystic fibrosis in the hospital, as well as outside the hospital and so I felt like, in terms of training about cystic fibrosis, I feel pretty comfortable with that. |
| Informal forms of preparation |
| Use information sheet sent with notification |
| There’s instructions saying specifically what the abnormality was that was found, and I think like next steps in terms of what the patient is supposed to do, which is helpful … I usually just follow the instructions that are written on there. |
| MDCH Web site for information about follow-up |
| I looked up the screen myself, and then I went to the website for the Michigan Department of Community Health to get more information about the follow-up. |
| Call specialist |
| We decided to call the University for you know, basically getting another opinion about the positive screen and we finally referred the patient for a sweat test to the cystic fibrosis center. |
| Internet search to refresh |
| I just went and refreshed myself with what does it mean if this comes back as this result, and what does it mean if this comes back as that result … And so that’s what I did before the family came back in, so but I was better informed to tell them. |

Abbreviations: PCP, primary care provider; MDCH, Michigan Department of Community Health.

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## Table 4

Illustrative Quotations: Difficulties Associated With Being First Point of Contact.

- Management of results
  - Unsure of how to direct parents
    - It was very helpful to have the plan already laid out for me in the material that I received from [the state] recommending a sweat chloride and referral to genetic counselor. I don't know that I would have thought of the sweat chloride…I would've thought maybe just the genetics counselor.
  - Ensuring parents pursue follow-up testing
    - Trying to get her down for the confirmatory test took that mom a month and that was just driving me crazy because I thought if this kid had cystic fibrosis, we really need to know … we scheduled it within a week of that newborn screening result, we had it scheduled at DeVos and she canceled, she canceled, she canceled, and so I think she was in denial, and of course they had a financial crunch so it's a little bit more difficult
- Content of conversation
  - Determining how much information to share before confirmatory testing
    - I've had one situation where the test was positive for the newborn screen, but then all of the testing after that was normal. And so from my experience, I tend to kind of talk in generalities, but then once we get a more specific diagnosis, I talk about the specifics at that follow-up visit
  - Influential factors in determining how much information to share
    - Number of mutations found on newborn screening (NBS)
      - I had the screening results that said heterozygous, and I was like "good hopefully everything is okay." But if it's homozygous that's just a little harder. I probably would not have called them on the phone, I would've just asked them to come in if it was homozygous and it was probably going to be positive on the sweat chloride, but that's a bigger deal.
    - Current health of child
      - I gave them very limited information for the pure fact that the mother was very hysterical and the child really had no problems. So I said, "you want to watch for breathing" which, because usually I've always seen the children before I get that test back. So I've already seen this child probably twice before I got that testing. She had no problems at all.
    - Parent emotional state
      - My first year coming out, I think it was during residency or something, somebody had said to me, "don't bombard these poor parents with numbers, they're not sleeping at night they're up every two hours they're not going to understand what you're saying."
- Addressing parents' questions
  - Recontact primary care provider (PCP) with additional questions
    - I give them my e-mail in this situation because I find that e-mail is a nice tool that, if something comes up in the middle of the night and you can't call the office, or maybe you could, but you just want to do something in an e-mail version.
  - Direct to specialists
    - I think the role of the general pediatrician is to let the family know that there's a concern and connect them to … Experts that can answer their question.
  - Give printed information
    - Then [I] go to the Michigan Department of Community Health website and print off the facts sheet for the family
  - Encourage Internet use
    - I gave them the CF Foundation information, which actually has a very good information about newborn screening and it tells exactly, how it's done, why it's is done, what happens when you get the results, and it also tells them that a positive newborn screen does not mean your baby has this condition. So I referred them to the CF Foundation website
  - Discourage Internet use
    - The one thing that I usually encourage them to do is don't look at anything until you had a chance to go and see the pulmonologist or to get the sweat chloride test done. Because you don't even know that this is real until all of those lab confirmatory types of things get done. And so, you might scare yourself reading things that won't even apply to you or your child. So I usually try to get them not to get on the Internet, because I think it's a scary thing, it can be just overwhelming then on the parents.

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## Table 5

Illustrative Quotations: Managing Parental Anxiety.

| |
|---|
| Making self available for parent questions |
| I try to answer as many questions as I can. I tell them that, “You can bring the child into the office, we’re open seven days a week at my office,” so they can come in any day that they want to and talk to me about it if they think of more questions. |
| Support parents through process |
| And I had to be honest with her and say, “I know what you’re talking about, but I don’t know enough information, this is out of my area of expertise. So what we will do is, if this is positive, we will send you to a specialist that will know a lot of these questions and I will stay very close to you in this process, so that we can kind of help navigate this together.” |
| Can’t be certain until child gets follow-up testing |
| I explained that this may be a false test, we have to run this test, if it confirms positive, then we will think about it. But I said don’t worry about this particular [screening] test right now. This is not that specific, now once you go there to the clinic and they’ll run the sweat chloride test and if that comes out to be positive, then we’ll be concerned. |
| Carrier result |
| The ones that are indicated as carriers, I’ll tell the parents, “This is heterozygous testing, meaning that they have a good end, not good genes, and that means your child probably isn’t going to have any symptoms from this.” |
| Focus on current health of child |
| This child was doing well, was feeding well, there was no history of meconium plug … So I’ve been around a while, I can reassure them that we didn’t see any other signs to be worried about at this time, but we still had to wait and see the results. |
| Emphasize early detection has best health outcomes |
| [I] told them the reason why we do a newborn screen, is because if we catch it early, then of course outcomes are much better, those kids do much better. |

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## Table 6

Illustrative Quotations: Primary Care Providers' (PCPs') Recommendations for Improving the Notification Process.

| Recommendations for improvement |
|---|
| Additional form of PCP notification |
| As a physician that takes pride in not missing any steps and being very vigilant, I'm always worried that I'm going to miss something like this. It was sent to me, but the fax machine ate it up, or something happens like that, then you get notified later. I don't know how else to do it, I don't know if e-mail's a better mode, I mean we're all on e-mail all the time. That would be my only suggestion that it would be kind of nice to maybe get notified by the state by e-mail … as a backup, I mean it's something that you need a paper trail for, but that would be a great backup. |
| Provide materials to distribute to families |
| I think what you guys should be able to do is provide a little handout, which contains information about the positive newborn screen and also the process of the sweat test so that parents have a little more information about what to expect when they go to the [CF] center. |
| Training for physicians |
| That would've been helpful, just to have had some kind of training … I don't know if you can get good training for how to break bad news to people because it's never good news to find out there's anything positive on that test. |
| Sample dialogue |
| What if there was something on [the notification] that was like a dialogue with high points? Like "these are the things that parents generally ask, these are ways that you could respond to those types of questions," and have that attached to that positive screening result. I think that might be a helpful thing to have. |
| Methods of ensuring parental understanding |
| Check for understanding, give opportunity to ask questions |
| I think it has to be an interactive process and so I think it's important to really leave room for the family to ask questions and to process the information, and to try to ascertain their level of understanding of what you've just told them. |
| Use of visual aids |
| I asked them, "Do you understand what I'm saying, that every pregnancy you have a one in four chance?" And they said they understood that and plus I draw it out on a piece of paper, I don't just tell them that, I actually write it on a piece of paper and show them the mathematical calculations. |
| Avoidance of medical terminology |
| I stay away from things that are confusing like big numbers and I talk more about practical information. I think it's better because they feel like they have the answers that make sense for their lives. I stay away from medical terms, I stay away from anything like that, because I think for the majority of people, they just want to know how is this going to fit in to my child's life. |