"Is it going to hurt?"

The impact of patient-provider interactions on children and their families during the diagnostic odyssey

Master’s thesis

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ABSTRACT

"Is it going to hurt?": the impact of patient-provider interactions on children and their families during the diagnostic odyssey

A thesis presented to the Department of Biological Sciences, Program in Genetic Counseling
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Pharmaceutical and therapeutic interventions to manage child distress are rarely offered to children undergoing minor medical procedures (such as venipuncture) despite overwhelming evidence that children find these procedures to be distressing. Reducing distress during medical appointments and procedures is crucial both for avoiding anticipatory anxiety before future procedures, and for improving the patient’s willingness to access healthcare as an adult.

The purpose of this qualitative study was to document the experiences of children experiencing multiple procedures during their diagnostic odyssey. We interviewed ten parents of children with neuromuscular disorders using a semi-structured interview guide to elicit information regarding the perceived benefits of obtaining a diagnosis, the child’s experiences with different medical procedures, and
parental perceptions (positive or negative) of their interactions with healthcare providers. We coded interviews based on a priori and emergent themes, and analyzed them based on the principles of interpretive description.

Three common themes emerged: (1) Having a diagnosis reduced strain on parents by validating their concerns, by enabling them to plan for the child’s future healthcare needs, and by allowing them to access established support networks. (2) Parents reported that even “minor” procedures, such as venipuncture and x-rays, were distressing for some children. Interventions were rarely offered for these procedures, and half of the parents did not believe that providers were aware that the child was distressed. (3) Parents did not see themselves as passive recipients of medical care, but as active and experienced members of their child’s healthcare team. They preferred providers who listened to their concerns and spoke to them respectfully.

While medical procedures are often distressing for children, they are a vital component of reaching a diagnosis. By asking parents about a child’s previous experiences, healthcare providers can identify those who would benefit from interventions. Furthermore, parents value the additional support available upon diagnosis. Facilitating communication with parents, a role that genetic counselors are well-suited for due to their training, may enable healthcare providers to offer more support to families during the diagnostic odyssey.

Keywords: diagnostic odyssey, neuromuscular disorder, anticipatory anxiety, distress, medical procedures, venipuncture, EMLA cream
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INTRODUCTION

Until about 1970, prevailing opinion held that children did not experience pain as strongly as adults did; consequently, little attempt was made to alleviate their distress during medical procedures (Baker & Wong, 1987; McCaffery, 1977). Since that time, significant progress has been made in pharmaceutical and therapeutic methods of reducing child distress. These methods are most often reserved for children undergoing highly invasive procedures, such as surgery or lumbar punctures. (Jay, Elliott, Ozolins, Olson, & Pruitt, 1985; Katz, Kellerman, & Siegel, 1980; Stephens, Barkey, & Hall, 1999). However, research reveals that many children find even “minor” procedures (such as venipuncture) to be highly distressing (Fradet, McGrath, Kay, Adams, & Luke, 1990; Humphrey, Boon, van Linden van den Heuvell, & van de Wiel, 1992).

One group of children who experience numerous medical procedures during the search for a diagnosis is those with neuromuscular disorders. The procedures may include, but are not limited to, blood tests, x-rays, echocardiograms, electrocardiograms (EKG), electromyography (EMG), and muscle biopsy. The “diagnostic odyssey,” the period of time between when a parent or provider first becomes concerned and when a diagnosis is finally reached, may last for months or years. The procedures involved throughout the diagnostic odyssey may be painful, uncomfortable, or frightening. Even procedures that the child has previously tolerated well may become distressing after a negative experience.
Reducing distress is crucial to avoiding an increase in anticipatory anxiety, which can heighten the perception of pain and contribute to an escalating cycle of fear and distress surrounding any and all future medical encounters (Kennedy, Luhmann, & Zempsky, 2008). Therapeutic interventions, including informing the child what will occur and how it will feel, and encouraging the parent to participate in supporting and distracting the child, may help alleviate child distress (Cohen, 2008). A topical analgesic called EMLA (Eucelic Mixture of Local Anesthetic) cream has been shown to significantly reduce the pain of venipuncture, especially when used in combination with therapeutic interventions (Kolk, van Hoof, & Fiedeldij Dop, 2000). However, pharmaceutical and therapeutic interventions are generally offered only after a child has already exhibited procedural distress. Unfortunately, “once a child has a negative initial experience there is a change in the mental ‘set point’ of his or her interpretation of that noxious stimulus... The data suggest that, if analgesics are used, it is critically important that they be effective the first time, especially for younger children” (Weisman, Bernstein, & Schechter, 1998).

Neglecting to address anticipatory anxiety has both short- and long-term implications for the health care of a child. Performing medical procedures on children who are distressed and resistant is more time-consuming than performing them on cooperative patients; it is also more upsetting for the child and parent. Children who have negative experiences are more likely to grow up into adolescents and adults who avoid health care (Ayers, Muller, Mahoney, & Seddon, 2011; Jones, DeMore, Cohen, O'Connell, & Jones, 2008). Because individuals with neuromuscular disorders require
lifelong medical care to maintain optimal health, improving childhood experiences can have significant long-term implications.

The goal of this qualitative study is to document the experience of children undergoing multiple procedures during their diagnostic odyssey. We interviewed parents of children with neuromuscular disorders to elicit information regarding the benefits to the parent and child of obtaining a diagnosis, the child’s experiences with different medical procedures, and interactions with healthcare providers that were positive or negative from the parent’s point of view. Data analysis revealed themes that will allow genetic counselors and other healthcare professionals insight into how to improve the patient-provider relationship, with the overall goal of providing better healthcare to pediatric patients and their families.
METHODS

INFORMED CONSENT AND METHODOLOGY

The Brandeis University Institutional Review Board approved the study protocol, which included a description of participant protection procedures. We employed qualitative methods in order to gain an in-depth and nuanced understanding of the participants’ individual experiences. The Boston Children’s Hospital Institutional Review Board approved the recruitment letter (Appendix A), which was mailed to individuals who had previously agreed to be contacted for future research projects through the Harvard Neuromuscular Disease Project (HNDP) at that institution.

SAMPLING METHODS AND STUDY PARTICIPANTS

We recruited participants for this study through the Harvard Neuromuscular Disease Project at Boston Children’s Hospital. Subject inclusion criteria were as follows: 18 years or older, fluent in English, caring for a child with a diagnosed or suspected neuromuscular disorder, and the primary caregiver for that child during medical appointments. Within this population, we employed purposive sampling to select participants whose children most closely fit the profile of the “ideal” subject: a child diagnosed with a less common form of muscular dystrophy within the last five years, after enduring an extended diagnostic odyssey characterized by multiple medical procedures performed between the ages of three and twelve years of age. A genetic
counselor employed by the HNDP mailed the recruitment letter (Appendix A) to potential study participants along with an opt-out card. The interviewer contacted individuals who did not return the opt-out card by phone. Of eighteen potential study participants, one phone number was not in service, six individuals did not return phone calls, one spoke primarily Spanish, and ten agreed to participate. We mailed or emailed the informed consent form (Appendix B) and questionnaire (Appendix C) to each participant and collected them prior to conducting the telephone interview. Each participant received a $25 gift certificate in appreciation of his or her contribution.

**INTERVIEWS**

We conducted and analyzed the interviews based on the principles of interpretive description, in which a clinical phenomenon is investigated for the purpose of “capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding” (Thorne, 2004). Based on previous literature regarding children’s experiences with medical procedures (especially the questions designed by Ayers et al. to assess needle-related distress (2011)), we designed a semi-structured interview guide with open-ended questions (Appendix D). The personal and professional experiences of committee members influenced the final content of the guide. The interview focused on the specific events of the diagnostic odyssey, the child’s reaction to medical appointments and procedures, and actions by healthcare providers that had a positive or negative impact on the child and/or parent’s experience. Before the study commenced, we pilot-tested the interview guide with the parent of a child who had experienced multiple medical procedures.
One investigator interviewed all participants using the same interview guide; however, the amount of time spent on each topic and the specific questions asked were dependent on the experiences of the individual participant. The interviewer employed a collaborative interviewing method, in which the “interview is conducted more as a conversation between two equals than as a distinctly hierarchical, question and answer exchange” (Ellis & Berger, 2001), with the goal of creating a more relaxed discussion and facilitating the participants’ comfort in sharing sensitive information. Interview duration ranged from 35 to 75 minutes.

**DATA MANAGEMENT AND ANALYSIS**

The interviewer digitally recorded all interviews, which were then transcribed by a professional transcriptionist. All documents containing identifying information were stored on a password-protected laptop.

We placed our data into ATLAS.ti (version 7.0), a software package for qualitative analysis of textual data (Friese, 2011). We coded interviews by assigning codes to sections of texts, phrases, or paragraphs based on *a priori* (from the interview guide) and emergent themes. As themes emerged, codes were merged or discarded, winnowing the original 125 codes down to 41 codes grouped into eight code “families.” Five code families provided the most meaningful data for this study: the diagnostic odyssey, types of procedures the child experienced, positive or negative experiences of those procedures, provider interactions, and parent advice to other parents or healthcare providers. We analyzed the information for common themes and patterns, as well as for variations among individual responses.
RESULTS

The participants in the study were all female; five affected children were girls and five were boys. One mother had two children with the same disorder, but the interview focused only on the older child. All of the families had more than one child.

Demographics and diagnoses for participants’ children are listed in Table 1.

Table 1: Demographics of Participant’s Children

<table>
<thead>
<tr>
<th>Gender</th>
<th>Current age</th>
<th>Diagnosis</th>
<th>Age at diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td>5-9 years</td>
<td>Congenital myasthenic syndrome</td>
<td>0-1 year</td>
</tr>
<tr>
<td>M</td>
<td>5-9 years</td>
<td>Duchenne muscular dystrophy</td>
<td>1-4 years</td>
</tr>
<tr>
<td>M</td>
<td>10-14 years</td>
<td>Duchenne muscular dystrophy</td>
<td>1-4 years</td>
</tr>
<tr>
<td>M</td>
<td>10-14 years</td>
<td>Duchenne muscular dystrophy</td>
<td>1-4 years</td>
</tr>
<tr>
<td>F</td>
<td>10-14 years</td>
<td>Congenital muscular dystrophy</td>
<td>1-4 years</td>
</tr>
<tr>
<td>M</td>
<td>10-14 years</td>
<td>Unknown myopathy</td>
<td>Undiagnosed</td>
</tr>
<tr>
<td>M</td>
<td>10-14 years</td>
<td>Unknown neuropathy</td>
<td>Undiagnosed</td>
</tr>
<tr>
<td>F</td>
<td>15+ years</td>
<td>Limb-girdle muscular dystrophy (Type 2)</td>
<td>4+ years</td>
</tr>
<tr>
<td>F</td>
<td>15+ years</td>
<td>Facioscapulohumeral muscular dystrophy</td>
<td>4+ years</td>
</tr>
<tr>
<td>F</td>
<td>15+ years</td>
<td>Bethlem myopathy</td>
<td>4+ years</td>
</tr>
</tbody>
</table>

Three main themes emerged from the interviews: the value to families of obtaining a diagnosis, the children’s experiences with medical procedures, and interactions between providers and parents.

**Theme: Value of a Diagnosis**

The first section of the interview gathered information about the diagnostic odyssey. The questions elicited information about the period between when the parent first became concerned about the child, through various medical appointments and procedures, until the time that a diagnosis was made. Parents spoke about the
procedures their child experienced, the emotional impact on the family, and their interactions with healthcare providers. They also spoke about the reasons that obtaining a diagnosis was important to them. Many of their reasons echoed those of medical professionals: initiation of treatment, participation in clinical trials, and reproductive planning (Ciafaloni et al., 2009). However, three additional subthemes emerged that are uniquely parent-centric: a sense of validation for the parents (that their concerns were legitimate), the value of a prognosis in preparing themselves and their child for the future, and the ability to tap into established support networks.

**VALIDATION**

Of the ten parents in this study, four remarked that obtaining a diagnosis gave them a sense of validation: they had suspected for some time that their child had a serious medical disorder, and the diagnosis gave it a name. Having their concerns initially dismissed by healthcare providers increased their anxiety, because they felt like the sole advocate for the child. Upon finally meeting the doctor who would diagnose her son, one mother remembers,

“He listened to me, and that was key. That was huge. It was a huge relief to have someone actually listen.”

Another, upon receiving a diagnosis, recalls,

“To hear those words... that was a scary moment... But in a sense, and this is going to sound really bad ... it was so confirming to me. I knew something wasn’t right.”

One parent recounted an especially harrowing experience, in which medical staff suspected that she was deliberately causing her child’s symptoms. During one hospitalization, an observer was stationed in her room:
“She treated me like I was the world’s worst mother… It was awful, awful, awful. Because I remember when we came upstairs after we got the diagnosis, I went right up to her and I said, ‘I told you I wasn’t trying to kill my child and I told you she had something rare…’ I was pissed… That was the worst.”

Children also benefited from having a diagnosis to explain their physical limitations. One mother recalled that her daughter had been told by her school gym teacher to “get over it” and “rise to the occasion”; once a diagnosis was made, the child was excused from activities that she was physically unable to perform. Rather than being penalized for her disability, she was validated for the effort she was exerting.

**PROGNOSIS**

Having a diagnosis enabled physicians to provide parents with a prognosis, allowing them to plan for the future. One parent, who first became concerned about her child in preschool but waited almost ten years for a definitive diagnosis, said,

“Since four years old we’ve really never known what to think. So, yeah it’s very stressful for the parent, especially because you don’t know what to plan for your child. You don’t know what to expect.”

Once they obtained a diagnosis, parents were better able to access physical therapy, occupational therapy, and community-based programs that provided financial support to modify the child’s environment (e.g. for wheelchair accessibility). They were also able to prepare their child for the expected progression of the disease. For the mother of a boy with Duchenne muscular dystrophy,

“When it was the point for him to be in a wheelchair full-time I thought it was going to be worse, and he took it easier than what I did. He was really calm about the whole situation, because I was talking to him about it constantly; I mean age appropriate of course.”

When the diagnosis was better than feared, parents experienced a sense of relief:
“I think we were all just waiting for the diagnosis, and honestly I was glad it’s not a death sentence.”

Even if the diagnosis was for a life-limiting condition, knowing allowed parents to coordinate appropriate medical care and prepare their child:

“She also knows that on some issues she has the ultimate power. For example... she made it abundantly clear that she had no plans, no desire, no interest in being on a trach or a vent long-term.”

**SUPPORT**

Having a diagnosis allowed parents to tap into established support networks.

One parent, whose child was first diagnosed with a form of muscular dystrophy and then had the diagnosis removed, recalls:

“We right away got involved with the [Muscular Dystrophy Association (MDA)] ... We did a walk for him for the organization... And then when we got this dis-diagnosis, the un-diagnosis, I never regretted a moment doing that for MDA ... It was an amazing, amazing time.”

Four parents reported that having a diagnosis allowed their child to participate in specialty camps and respite groups, and to meet other children with similar challenges.

For very rare disorders, even those with only a few diagnosed cases worldwide, parents connected through internet-based support groups to compare experiences and share information.

**THEME: EXPERIENCES WITH MEDICAL PROCEDURES**

Before the interview, parents filled out a brief questionnaire about the types of medical procedures their child had experienced (Appendix C). The next section of the interview reviewed this questionnaire, and elicited additional information about how the child reacted to each procedure. Parents were also asked questions about the most
distressing and least distressing procedures that their child experienced, and about if or how the child’s reaction to a frequent procedure changed over time. The interviewer elicited information about three subthemes: which procedures were most distressing for children, which actions by healthcare providers or parents reduced child distress, and how children manifested distress in relation to experiencing a procedure.

**DISTRESSING PROCEDURES**

After reviewing the procedures experienced by the child, parents were asked to elaborate about ones that were especially distressing for the child (Figure 1).

![Number of children who experienced each type of medical procedure, and the number who found each type distressing](image)

**Figure 1: Number of children who experienced each type of medical procedure, and the number who found each type distressing**

For most procedures, the experiences of children varied; however, all of the children who experienced lumbar puncture or electromyography (EMG) found these procedures distressing. One mother said, of her daughter’s four experiences with lumbar puncture,

“I don’t know that I could do that to her again unless it’s life or death.”
Of the EMG, the same mother described her child as:

“Screaming bloody murder and looking at us; she was looking for help. She looked like a caged animal. It was hell.”

Two parents complained that providers had not prepared them for how distressing an EMG could be for a child:

“As a parent I didn’t know to prepare her. I didn’t prepare her for that. I didn’t know how bad it was going to be myself.”

For surgery and muscle biopsies, parents reported that, while the procedures were difficult, healthcare providers had told them what to expect, and children received adequate preparation and pain management. However, for procedures considered less invasive, such as blood tests and x-rays, little preparation was offered:

“When she went for surgery and she went for her biopsy and those things were just done wonderfully by the hospitals. She was distracted. We were prepared. But it was like for the blood work and the tests that was pretty much up to me to prepare, right?”

Parents whose children were distressed by blood tests described them as “freaking out” or “horrified.” For some of these children, blood tests were always difficult, and for others, a single difficult experience, in which the phlebotomist attempted repeatedly to locate a vein, triggered the reaction. Similar experiences were reported for IV. Only one parent reported that her child was regularly offered EMLA cream (a topical analgesic) before venipuncture.

Of the nine children who had experienced x-rays, three found them to be distressing at least once. Children with neuromuscular disorders, who are losing the ability to walk and to sit, have difficulty positioning themselves for this procedure. One parent said,
“The x-rays are actually really difficult, because he’s in a wheelchair so you’ve got to move him into another seat and you’ve got to get him to sit up...That’s hard for him to do, and he has to sit for a while. Those are hard, the chest x-rays.”

Another mother wished that she had been offered an aide to assist her in positioning her twelve-year-old for seated x-rays to evaluate him for scoliosis:

“The chair was so small and the way that his legs are, like I said, his knees are a bit contracted, he can’t sit straight. And I was trying to hold him at the same time, and it was just a matter of he was scared that he was going to fall down off the small chair.”

**POSITIVE INTERVENTIONS**

We asked parents to elaborate about procedures that were less distressing for their child than they had expected, and specifically about actions on the part of the parent or healthcare provider that improved the experience.

The most common techniques that parents used to help their child manage anxiety or fear related to medical procedures were distraction, giving the child information about what would occur, and rewarding them after the procedure. For some procedures (e.g., surgery), the child was given medication to alleviate pain or reduce anxiety. Some parents brought a friend or a comfort object (such as a stuffed animal). Others gave the child some control over certain aspects of the procedure, such as whether to sit beside the parent or on her lap (Figure 2).
Figure 2: Number of parents who reported the use of each technique to manage child distress during medical procedures

Children were less distressed when familiar providers performed the medical procedures. Six mothers reported that her child liked returning to environments where the staff knew him or her, and that healthcare providers who were familiar with the child were better able to meet his or her needs.

Parents also reported that the child was better able to tolerate procedures if the environment was less stressful. One parent described her child as “intimidated” by having too many people in the procedure room. Another parent described a distressing and ultimately unsuccessful attempt to place an IV for an MRI:

“It was the fact, I think, adults were trying to do something and ... the adults were failing at it, which if you have small veins what can you do? ... Part was the conversation in the room.”

Having even one calm person in the room eased the stress for parent and child, as described by the same parent about a different incident:

“[The nurse] was like an island of calm in the sea of all these people who were like stressed out and kind of getting really concerned... But he says, ‘There’s
EVALUATING CHILD DISTRESS

When asked how the child manifested pre-procedural anxiety, parents described behaviors that included talking excessively, asking questions, making noises, yelling, crying, squirming, grimacing, sighing, and getting quiet. Half of the mothers said that, while she knew her child was anxious, she did not believe that the healthcare providers were aware:

“I mean, he never seemed that anxious... In the waiting room he didn’t seem out of control or anything... I think it’s probably more subtle with him.”

One parent describes the pitch of her child’s voice changing:

“And the way she would say, “Oh, okay” it would be a higher pitch kind of, like I could tell she’s saying it’s okay, but it’s probably not okay.”

Another also described a subdued reaction:

“She gets quiet, but... I could tell because I was her mom.”

Four of the parents remarked that this child was better able to handle medical procedures than his or her (unaffected) siblings would have been:

“So I think if this health issue had to happen to any one of my children, and I know this is going to sound horrible, I’m going to go to hell for this, but... I would definitely pick him. I don’t think any of the other ones would have been as strong as he was during this.”

THEME: INTERACTIONS WITH PARENTS

In the final part of the interview, we asked parents what would have improved the diagnostic odyssey and what advice they would offer to another parent or a healthcare provider. At some point in the interview, nine of the ten parents spoke of the
need to be an advocate for the child. For some, this was in pursuit of a diagnosis, and for others, it was while requesting services after a diagnosis. These parents did not see themselves as passive recipients of a diagnosis or instructions delivered by a doctor, but as an integral part of the child’s healthcare team. Consequently, they objected to healthcare providers who did not trust their intuition, listen to their concerns, or who spoke to them in an incomprehensible or condescending manner.

**TRUSTING PARENTS’ INTUITION**

The three parents whose sons were diagnosed with Duchenne muscular dystrophy (DMD), the most common type of muscular dystrophy in boys, generally had their concerns promptly addressed when brought to the attention of the pediatrician. By the time each boy was three years old, he was receiving care through a specialty clinic. The other parents all faced a longer or more frustrating search for answers. A significant majority (six of the remaining seven) complained about healthcare providers not taking their concerns seriously. One parent reported that her questions about her daughter’s toe-walking were brushed off for years with the comment “she’ll outgrow it.” Another remembers that,

“The pediatrician lost her cool with me and told me I was an overanxious mother…. She gave me a big lecture. I still have the paper, a copy of the report that she gave [to the hospital]. ‘Parents are demanding the child be seen at Children’s. It is not necessary.’”

Repeatedly, parents advised physicians to trust the parent’s intuition:

“I think the key is listening to the parents and if they say that there is this issue going on or this is going on or ‘I know that’s not right,’ then I think listening to the parents... knowing that they know their child.”
Parents spent far more time with the child that any doctor and were most invested in their well-being; they were offended when medical professionals peremptorily dismissed their concerns after a cursory exam.

LISTENING

Parents praised the doctors who took time to listen. They felt that the best providers were those who did more than just order tests or proclaim a diagnosis; they also listened to the parents’ concerns, questions, and observations about the child. One parent summed up the feelings:

“We’ve had very good doctors that take their time and they really spend a lot of time finding out about [our son] and what he needs and what is going on... But we’ve met those few doctors that you spend more time traveling to the appointment and you see the doctor for like not even five minutes... I get so upset about that... I feel like “Oh, okay, I’m just a number here and they’re just trying to get through their day.”

TALKING TO PARENTS

The manner in which providers spoke to parents was also important. One parent recounts her meeting with the provider who would eventually diagnose her daughter:

“He was the best one. He wasn’t arrogant and entitled like most of them were. He was very passive, very type B, very exactly what my husband and I needed. He listened to us. He never raised his voice to us. He never talked to us as if we were stupid.”

Others also complained about doctors making them feel incompetent:

“Stop using such technical words to us. We’re not as smart. We didn’t go to school. If we did we would be able to diagnose our own children. I cannot tolerate any more a doctor that will sit there and throw all their... fancy Latin words to you... Explain it to me in a way I can understand it, not in your medical terms, because that still is foreign to me. It drags the visit on longer if you have to keep going, ‘Huh? What does that mean?’ because then you start feeling rude and very ignorant.”
“I saw one specific doctor that was very agitated and very frustrated with me... He was just firing off all these questions and I got really flustered... That was a really horrible experience.”

When doctors impressed parents, it was generally not for making the diagnosis, but for the way they treated the parent and child. Parents especially appreciated being included as part of the team treating their child or seeking a diagnosis:

“I will never ever forget her... She pulled us aside... and she said, ‘Listen, these are the appointments you need to make. These are the people you need to see. Don’t give up on her. Call, make the appointments, keep going after it.’”

“[The doctor] was pretty sure that [my child] was going to make some kind of medical magazine or book of some kind, because his case was just so rare... He was outreaching to other children’s hospitals to talk to their muscular doctor people.”

“I like the fact that [his neurologist], he’s always letting me know if there is any research or anything... and I feel very open to talk to him about any of those things... That has made it special.”

In other words, the healthcare providers that parents appreciated were not just the ones who were able to make a diagnosis or provide medical care for their child, but were able to support the child and parents as they navigated the complexities of managing a serious medical condition.
DISCUSSION

In this study, we interviewed ten mothers of a child with a neuromuscular disorder in an attempt to gather information about the diagnostic odyssey from the parental perspective. The themes and subthemes that emerged suggest ways that healthcare providers can improve this difficult experience for families. These suggestions include assisting parents in accessing support, minimizing child distress during medical procedures, and including parents as part of the child’s medical team. All of these suggestions fall within the range of expertise of genetic counselors.

THEME: SUPPORTING THE FAMILY

Parenting a child with a disability is significantly different from parenting a healthy child, in terms of care giving, supervision, and managing healthcare (McCann, Bull, & Winzenberg, 2012). For many of the parents in this study, the care giving needs of the child have increased with age, rather than decreased, as the child has lost functional ability. For some, constant vigilance is required for signs of illness that may rapidly worsen. Medical care involves lengthy trips to visit specialists, and coordination of medication or adaptive equipment. These additional parenting responsibilities exact an emotional toll on parents and families, and also consume a significant amount of time. Not surprisingly, the three subthemes that emerged all reflected the additional supports needed to alleviate the strain placed on families of children with a disability.
Support for the families in this study came in a number of different forms. Initially, the diagnosis from the healthcare providers gave the parents long-awaited confirmation of what their intuition was telling them. Up until that moment, they felt isolated, as the only people concerned for the child. To finally have the confirmation from a doctor that they had been correct to keep pursuing a diagnosis was, in the words of one parent, “both scary and a relief.”

Obtaining a diagnosis allowed parents to begin planning for the future. Whether the diagnosis was of a disabling or a life-limiting condition, parents preferred knowing the prognosis to facing an uncertain future. Parents were able to pursue therapies for their child, make modifications to the child’s environment to accommodate future mobility issues, and begin preparing the child for future challenges. The whole family had time to adapt to a different lifestyle.

Finally, parents were able to make contact with other parents through established support networks. The Muscular Dystrophy Association (MDA) provides both local and online support groups, as well as summer camps for children, where families can exchange stories, share experiences, and learn from each other. One parent of a child with a very rare disorder was able to connect through Facebook with other families sharing not only the same disorder, but also the same underlying genetic mutation, to compare treatment strategies. While a child’s physical needs may be separately addressed without a diagnosis, the family’s need for support was better met with a diagnosis.
Healthcare providers may prefer to delay providing a diagnosis until there is clinical or genetic confirmation, particularly if the label would not alter medical management. However, this study demonstrates that even a provisional or differential diagnosis may benefit parents. Taking the time to explain to parents the diagnosis being considered, the symptoms that do or do not support the diagnosis, and the other possible diagnoses in the differential may be time consuming. However, while a diagnosis such as “unknown muscular dystrophy” may seem unhelpful from a medical management standpoint, it allows the parent to access all the resources provided by the MDA. Factors other than medical management should be considered when deciding how aggressively to pursue a diagnosis for a child.

**Theme: Minimizing Procedural Distress**

During a diagnostic odyssey, physicians order medical procedures that will confirm or rule out diagnoses. In choosing which tests to perform first, a physician may prioritize ruling out causes for which early treatment may mitigate or eliminate symptoms (such as metabolic disorders). Procedures that are less invasive and more likely to return actionable results are usually ordered before more invasive procedures that diagnose disorders without currently available treatment. More common causes are ruled out before rarer diagnoses are considered. Children in the study population had all undergone numerous medical procedures, ranging from non-invasive procedures (such as imaging and EKGs) to invasive procedures (such as surgery and lumbar punctures).
Lumbar punctures and EMGs were highly distressing for the few children who experienced them. In these cases, parents reported that the child was not offered adequate pain management nor support. Parents of the seven children who had surgery and muscle biopsies generally felt well supported and prepared by the hospital even though their children expressed anticipatory anxiety and post-procedure pain.

More than half of parents reported that venipuncture, including blood tests and IVs, were distressing for their children. Providers consider these procedures to be non-invasive (“just a blood test”), despite considerable evidence that children find them distressing (Fradet, et al., 1990; Humphrey, et al., 1992). Two-thirds of children in a British inpatient study reported that venipuncture was the worst thing that happened in the hospital, with some children likening it to being stabbed or hit with a hammer (Hands, Round, & Thomas, 2010).

Parents in this study reported using a variety of techniques to manage their child’s distress during venipuncture; each seemed to have developed a system that worked for her child. Many of these have been studied and found to be effective (giving information, distraction, allowing limited control over the procedure), but none of the parents seem to have been offered professional assistance in preparing the child for this procedure. For example, not one of the ten parents reported using relaxation or imagery as a therapeutic techniques, despite evidence that both are effective in relieving distress (Cohen, 2008; Powers, 1999; Stephens, et al., 1999).

While muscle biopsy and surgery are infrequent occurrences, blood tests and IVs are a regular part of care for some children in this study. A few children handled these
with minimal distress, but for most, this was their major concern during each physician visit. After a single negative experience, with repeated failed attempts to access a vein, children experienced increased fear of doctor appointments. Only one parent reported that her child was consistently offered EMLA cream, despite evidence that this topical analgesic significantly reduces child distress during venipuncture (Cohen et al., 2001; Kolk, et al., 2000). One of the arguments against offering EMLA cream is that it delays the procedure for 30-60 minutes while the analgesic takes effect. However, seven of parents in this study said that they “made an event” out of the appointment, by taking the child for lunch or another outing while in the city; for these parents, waiting a little longer for the procedure, or returning in an hour for it, might not be a major inconvenience. Parents should be educated about EMLA cream and other topical analgesics and allowed to decide if this would be beneficial for the child.

Given that this population of children will likely experience numerous needle-sticks during care, investing some resources in educating parents about effective management would have long-lasting benefit to the child and the caregiver. Ideally, these interventions would be offered the first time the procedure is performed, to prevent anxiety from developing; however, they have been shown to benefit distressed children at any time.

One surprising finding was that three children found x-rays to be distressing. While the x-ray itself is not painful, the challenges of positioning children with mobility issues can cause both physical discomfort and concern about falling. For one child, the x-rays were performed in the post-operative period, and were painful due to the
complications of working around a back brace and chest tube. While a typical x-ray might not be painful for her, she may still fear the procedure due to negative memories.

If providers could predict which medical procedures would be distressing for children, they would be able to offer strategies for parents to implement before the procedure. How is a provider to make this prediction, when even painless procedures such as x-rays may be distressing given the child’s previous experience or limitations? Some manifestations of anxiety, such as nausea, vomiting, crying, screaming, and resisting intervention are fairly obvious (Blount et al., 1997; Dolgin, Katz, McGinty, & Siegel, 1985). However, others are more subtle, and children may be unable or unwilling to verbalize their feelings (Logan, Claar, & Scharff, 2008; Perrin & Gerrity, 1981). In this study, half of the parents reported that providers were not able to tell if the child was distressed. Clearly, relying on verbal or non-verbal cues from the child will not always reflect the child’s actual reaction.

Parents also may not volunteer this information, especially if they are unaware that pharmaceutical or therapeutic interventions exist. Almost half of the mothers in this study described their affected child as more able to manage procedures than his or her siblings, further decreasing the likelihood that she would request interventions. Asking the parent directly may be the best way to assess the child’s reaction to procedures. A simple question, like “How does she usually do with blood tests?” or “Has he had x-rays recently? How did that go?” will allow the provider to troubleshoot potential difficulties or request assistance for the child. Many hospitals now have Child Life Specialists available to aid children with therapeutic interventions or alternative
positioning for comfort. A relaxed and comfortable child results in faster procedures, not just once, but also in the future.

Furthermore, the procedure environment should be designed to minimize child distress. Debra Wagers, a Certified Child Life Specialist, has developed a campaign called “One Voice,” composed of elements endorsed by this profession: educating and involving parents in procedures, distracting and validating the child, and keeping the volume level to a minimum by eliminating extraneous personnel and appointing one provider to be the sole voice heard in the room during the procedure (www.onevoice4kids.com). The parents in this study echoed the need for calm procedure environment, and also stated that their children were more comfortable when a familiar provider performed the procedure. If the goal is to treat a child so that he or she grows up into an adolescent or adult who remains compliant with healthcare recommendations, then improving the procedure experience will promote this outcome.

**Theme: Including the Parent as Part of the Team**

Parents in this study considered themselves an integral part of their child’s healthcare team. As the person who was most intimately involved in the child’s care, and who saw the physical and emotional toll that this disease took on the child day after day, they wanted their voice heard. As one mother said, “you’re just seeing a snapshot of their life.”

Specifically, parents wanted healthcare providers to trust the parent’s intuition regarding their child’s symptoms and to listen to their concerns. Parents objected to
healthcare providers who spoke over their heads (using complex medical terminology) or spoke down to them (treated them “as if we were stupid”). In some ways, this can be thought of as a difference between language and content: parents may not speak the same “language” as the healthcare professionals (they may need medical terms defined, or need “layman” terms), but they are specialists when it comes to their child’s specific medical needs. The mothers in this study discussed managing complex pharmaceutical regimens (both oral and IV), wheelchairs and other mobility devices, enteral feedings, and home- and school-based therapies. Treating them as recipients of healthcare rather than as active participants minimizes the parent’s contribution.

Allowing the parent time to discuss what is happening at home enables the healthcare team to have a better sense of the challenges facing the family. Genetic counselors have the training to engage parents in this type of conversation. This discussion may suggest small changes to the treatment regimen, or targeted interventions, that improve compliance and reduce stress. For instance, recommendations for a home nurse to help organize medications once per week or a referral to a family therapist to address the concerns of unaffected siblings may benefit these families. A referral to an organization that trains therapy dogs may grant the child some independence, or a connection to respite care may allow parents time to work on a strained marriage.

While the challenges facing families of children with neuromuscular disorders may seem enormous, these parents remembered (often by name) the providers who took extra time to show that they cared. This study demonstrates that healthcare
providers can improve the well-being of patients and the experience of the diagnostic odyssey by reducing the child’s distress during medical procedures, and by validating the work of the parents through their interactions with them.

LIMITATIONS

Limitations of this study included the small sample size and diverse demographics; children of the participants were of differing ages, had different diagnoses, and each experienced their procedures at different ages. Future studies should include a larger sample size with more uniform demographics. Furthermore, the participants were recruited from one institution; all lived in major metropolitan areas and had access to hospitals focused on children and to specialists in neuromuscular disorders. The experiences of parents in rural areas or areas with less specialized healthcare providers would undoubtedly be a valuable addition to the study findings. Finally, further investigations of the experiences of parents of children with other diagnoses would allow these findings to be applied in a broader context.
Parents of children with neuromuscular disorders were interviewed about their experiences during the diagnostic odyssey. Three themes emerged: (1) Obtaining a diagnosis for the child benefited the family in ways unrelated to medical management or reproductive planning. Parents felt a sense of relief that their child’s symptoms had a name, they were able to plan for the future, and they were able to tap into established support networks. (2) Children often found even “minor” or “non-invasive” medical procedures to be distressing. Therapeutic or pharmaceutical interventions were rarely offered to these patients, despite the proven efficacy in reducing anticipatory anxiety before future procedures. Because many of the parents reported that their child exhibited anxiety in ways that medical personnel may not notice, parents should be asked about their child’s previous experiences and educated about the availability of interventions to reduce distress. (3) Parents did not consider themselves to be passive recipients of medical care, but saw themselves as active and experienced members of their child’s healthcare team. They preferred providers who included them in decision-making, who spoke to them in clear language in a non-condescending tone, and who took the time to understand how the disease impacted all aspects of family life.

While medical procedures are often distressing for children, they are a vital component of reaching a diagnosis. By asking parents about a child’s previous
experiences, healthcare providers can identify those who would benefit from pharmaceutical or therapeutic interventions, improving long-term health outcomes for these children. Furthermore, parenting a child with a disabling or life-limiting condition is a challenging experience, and parents value the additional support available upon diagnosis. Facilitating communication with parents, a role that genetic counselors are well-suited for due to their training, may enable healthcare providers to identify support resources that are available to families during the diagnostic odyssey, alleviating strain on the entire family.
REFERENCES


APPENDIX A: CONTACT LETTER

October 24, 2012

Family of Patient 1
555 Any Street
Boston, MA 02115

Dear Family of Patient 1:

My name is Nikkola Carmichael, and I am a graduate student of Genetic Counseling at Brandeis University. I am collaborating with the Harvard Neuromuscular Disease Project in the Program in Genomics at Boston Children's Hospital on my thesis project. As a participant in the Harvard Neuromuscular Disease Project research study, you gave permission for the research team to contact you for future studies. The study team is now contacting you on my behalf to determine if you would be interested in participating in my thesis project entitled “Child Reactions to Medical Procedures: Implications for Genetic Counselors and Health Care Professionals”.

The goal of my thesis project is to explore how children react to medical procedures at different ages. The information will help genetic counselors and other medical professionals understand the impact of these procedures from the parent's point of view, and improve the resources we offer to children undergoing these procedures in the future.

Participation is voluntary and open to parent/guardian(s) who:

- are 18 years of age or older
- have a child who was diagnosed with a neuromuscular disorder between 3 and 12 years of age
- have a child who was diagnosed with a neuromuscular disorder within the last 5 years

Participation will include a brief questionnaire to assess eligibility, and a phone or in-person interview. The interview will be audio taped and may last up to 1 hour. Participants will be thanked for their time with a $25 amazon.com gift card.

We would like to contact you about this research project, but do not want to impose on you if you are not interested. Letting us contact you does not mean that you have agreed to be in the study, just that you are willing to discuss it with us further. If you do NOT want to be contacted, please return the enclosed addressed postcard signifying that you do NOT want us to call or email you about this research project.

Please feel free to contact us at any time by phone or email should you have any questions regarding the study.

Thank you for your time,

Elicia Estrella, MS, CGC, LGC
Harvard Neuromuscular Disease Project
Program in Genomics
Children's Hospital Boston
617-919-4552/elicia.estrella@childrens.harvard.edu
Encl.

Nikkola Carmichael, BA
Genetic Counseling Graduate Student
Brandeis University
Waltham, MA
Nikkola@Brandeis.edu
INTRODUCTION
Nikkola Carmichael is a student at Brandeis University in the Genetic Counseling Master’s degree program. Elicia Estrella is the study coordinator of the Harvard Neuromuscular Disease Project (HNDP) at Boston Children’s Hospital and a licensed genetic counselor. We are conducting a research study by interviewing parents of children with neuromuscular disorders. We want to learn about how children react to medical tests, such as blood tests, biopsies, and EMGs that are a part of the process of getting a diagnosis.

You are being invited to participate in this study because you are the parent or guardian of a child with a neuromuscular disorder. Taking part in this research study is completely your choice. You should not feel any pressure to participate. You can decide to stop taking part in this research study at any time for any reason.

Please read all of the following information carefully. Ask any questions that you have about this research study. Do not sign this consent form unless you understand the information in it and have had your questions answered to your satisfaction.

If you decide to take part in this research study, you will be asked to sign this form. You will be given a copy of the signed form. You should keep your copy for your records. It has information, including important names and telephone numbers, to which you may wish to refer in the future.

PURPOSE OF STUDY
The purpose of this study is to learn about how children react to and cope with medical tests that are a necessary part of getting a diagnosis. We want to hear about how your child reacted at different ages and to different tests. We hope that we can learn from parents/guardians about what helped their children get through different medical tests. This information will be helpful for genetic counselors and other medical professionals who order these tests.

PROCEDURES TO BE FOLLOWED
The study will consist of one interview that will last up to one hour. We will ask you questions about your child and the medical tests s/he has experienced. We will also ask specific questions about why you think some tests were difficult and other tests were easy to get through for your
child. The interview will be audio recorded and transcribed for analysis. Unfortunately, if you do not wish to be audio recorded, we will be unable to continue with the interview since the transcript is imperative for data analysis. If you do not want to answer a particular question, just let us know and we’ll move on to the next one. Participation is voluntary.

RISKS
The only risk to you is if you get anxious or upset when you are discussing this information. If you become upset, you may choose not to answer a question or to stop the interview. Alternatively, we can recommend a genetic counselor for you to speak with about these feelings.

BENEFITS
There will be no direct benefit to you for your participation in this study. We hope that information from this study will help us gain a better understanding of children’s reactions to medical tests. This insight will enable genetic counselors and other medical personnel to identify ways to improve these experiences for children.

ALTERNATIVES
The alternative is to not participate in this research study.

PRIVACY AND CONFIDENTIALITY
Each participant will be assigned a unique identifier. The only information linking an identifier to a participant will be stored temporarily on an encrypted laptop and in hardcopy form in a secure file cabinet in the Brandeis University Genetic Counseling program offices. All study information will be destroyed once interviews are finished and evaluated.

PAYMENT
You will receive a $25 gift certificate to Amazon.com for participation in the research study as a gesture of appreciation for your time and expertise.

COST
There will be no cost to you to participate in the study, other than the time it takes to be interviewed.

WHOM TO CONTACT
If you encounter any problems related to study participation or have questions about the study, you may contact the Student Researcher, Nikkola Carmichael, at nikkola@brandeis.edu.

You may also contact the Principal Investigator for this project, Elicia Estrella, MS, CGC, LGC, at Elicia.Estrella@childrens.harvard.edu.

If you have questions about your rights as a research study subject, contact the Brandeis Committee for Protection of Human Subjects by email at irb@brandeis.edu, or by phone at 781-736-8133.
PARTICIPANT’S STATEMENT

I have read this consent form and have discussed with Nikkola Carmichael the procedures described above. I have been given the opportunity to ask questions, which have been answered to my satisfaction. I understand that any questions that I might have will be answered verbally or, if I prefer, with a written statement.

I understand that my participation is voluntary. I understand that I may refuse to participate in this study. I also understand that if, for any reason, I wish to discontinue participation in this study at any time, I will be free to do so.

If I have any questions concerning my rights as a research subject in this study, I may contact the Brandeis Committee for Protection of Human Subjects by email at irb@brandeis.edu, or by phone at 781-736-8133.

I have been fully informed of the above-described study with its risks and benefits, and I hereby consent to the procedures set forth above. I also consent for my interview to be audio recorded. ___

I understand that as a participant in this study my identity and data relating to this research study will be kept confidential.

________________________
Date Participant’s Signature

________________________
Date Student Researcher Signature
# Questionnaire

Name of child: __________________________

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APPENDIX D: INTERVIEW GUIDE

Interview guide

1. INTRODUCTION:

Thank you for agreeing to be interviewed today. I appreciate your taking the time to speak with me. Your experiences are very valuable to help guide genetic counselors and other healthcare professionals when explaining and implementing medical procedures in children.

Participation is voluntary. I will be recording our interview, so I do not have to take notes and I can refer back to as I analyze the information. All results will be reported anonymously, and I will be focusing on trends rather than the experiences of any specific parent.

I’ll ask you questions about how your child reacted to different medical procedures. I’ll also ask you about the interactions between healthcare providers and your child. I hope that this can just be a conversation between us about your child’s whole medical journey, so that I can understand any changes that happened over time. However, since we only have an hour, I may need to direct the conversation if we start to get off track.

2. BACKGROUND

- First, I would like to know a little bit more about your family. How many children do you have? How old are they?
- How old are you? What is your occupation? Do you take your child to most appointments?
- Tell me a little more about [the affected child]. What are his/her specific health challenges just now?
  - To better understand your child's experiences around health testing, how would you describe his/her temperament? [Examples if necessary: calm or energetic, intense or laid-back, easy-going or anxious]
  - How does s/he normally react to stress?
  - Any other comments about his/her personality?
3. DIAGNOSTIC ODYSSEY OVERVIEW

- Thinking back to when you first became concerned about your child’s health, what first caught your attention? Can you tell me more about that? [Make sure to find out the child’s age at the time.]
- Who was the first medical professional you went to with your concerns? Can you tell me about that?
- Can you walk me through what happened after that? [Prompts: Were you referred to a specialist? Did you get a definitive diagnosis? What procedures were ordered as part of reaching a diagnosis?]

4. CHILD’S REACTION TO MEDICAL APPOINTMENTS

- Do you tell your child about a medical appointment in advance? How far in advance? Have you always done that?
- Can you describe how do you generally prepare your child for appointments? Has this changed over time?
- Describe your child’s demeanor/behavior before medical appointments. [Clarification question: is s/he generally worried and anxious, or generally relaxed?]
- Have you ever missed or been late to an appointment because your child was upset? Can you tell me about a time this happened?
- How do you know when your child is anxious or distressed? [Clarification questions: Does s/he ask lots of questions, cry, scream, need to be restrained, complain, ask for hugs, complain of a stomach ache or headache, throw up, have nightmares?]
- What do you do to help calm your child?
- Does your child have any special strategies that help him/her relax when s/he is anxious or distressed? [Clarification questions: Does s/he have a favorite toy, blanket, or stuffed animal, does s/he listen to music, watch a video, play a computer game?]
- Do you ever ask for help from medical personnel if your child is upset before or during a procedure? Would you like them to help?
• Were you ever offered help by medical personnel if your child was upset? [For instance, breathing exercises to help the child relax, distraction with toys or a video, Child Life specialist]. Can you describe the impact of this?

• Does your child talk about procedures after they have occurred? In what way? [for instance, remembering what occurred vs. expressing emotion]

5. OVERVIEW OF THE PROCEDURES EXPERIENCED BY THE CHILD

From our pre-interview questionnaire, I see that your child has experienced these procedures: [summarize the procedure types]. I would now like to talk about your child’s reactions.

6. PROCEDURE RESPONSES: NEGATIVE (MOST DIFFICULT OR STRESSFUL)

• Of the procedures you listed, was there one that was especially difficult and/or stressful for your child?

• Walk me through what happened. [Find out where the procedure was performed, whether the child knew the person who performed it, who else was present]
  o How did your child first find out that the procedure would occur?
  o Tell me more about how she reacted between then and when the procedure started.
  o How did your child react during the procedure?
  o How did your child react after the procedure? What did s/he say about it later?

• Why do you think this procedure was so difficult and/or stressful for your child?

• How do you think your child would describe this procedure? Would s/he also identify this as the most difficult and/or stressful procedure?

7. PROCEDURE RESPONSES: POSITIVE (LEAST DIFFICULT OR STRESSFUL)

• Of the procedures we’ve discussed, can you tell me about one that was much less difficult (easiest?) for your child than you expected it to be? [Clarification: you thought it would be really difficult, but it ended up not being so bad]
• Walk me through what happened. [Find out where the procedure was performed, who performed it, who else was present]
  o How did your child first find out that the procedure would occur?
  o Tell me more about how she reacted between then and when the procedure started.
  o How did your child react during the procedure?
  o How did your child react after the procedure? What did s/he say about it later?

• Why do you think this procedure was so positive for your child?

• How do you think your child would describe this procedure? Would s/he agree with you?

8. EXPLORING A FREQUENT PROCEDURE

[I will select a procedure that was performed multiple times at different ages.] I would like to hear more about how your child reacts during ______.

• Let’s begin with one of the first times your child had this procedure. Walk me through it, starting with when your child found out that it would occur. [Confirm the age of the child at the time.] Did you give him/her a reward after the procedure was complete?

• Now let’s jump forward (a couple of years?) to another time that your child had this procedure. Can you walk me through how it was then? What was the same? What was different? Why do you think those things changed?

• Let’s do another jump forward, to the most recent time your child had this procedure. How is it now? What is the same or different? If it changed, why do you think these changes occurred?

• Was there one time that this procedure was more difficult for your child than others? Explain to me what you think was different about that time.

• Was there one time that this procedure was less difficult for your child than others? Explain to me what you think was different about that time.
9. THANK YOU, WRAPPING UP, ETC.

- Knowing what you know now, is there anything that you would have done differently?
- What advice would you give to another parent just starting this journey?
- Is there anything that you would like healthcare professionals to know about your experience?
- Would it be all right if I contact you by email or telephone if any questions come up when I review our conversation?
- Would you be interested in knowing the results of this study when it is complete? I would be happy to share them with you.
- Thank you for participating!