I, Amy R. Gladstone, hereby submit this original work as part of the requirements for the degree of Master of Science in Genetic Counseling.

It is entitled:
Assessing the Genetic Counseling Needs of Parents who have Adopted a Child with Duchenne or Becker Muscular Dystrophy

Student's name: Amy R. Gladstone

This work and its defense approved by:

Committee chair: Robert Hopkin, MD

Committee member: Martha Walker,
Assessing the Genetic Counseling Needs of Parents who have Adopted a Child with Duchenne or Becker Muscular Dystrophy

A Thesis Submitted to the Graduate School of the University of Cincinnati in Partial Fulfillment of the Requirements for the Degree

Master of Science

In the College of Medicine at the University of Cincinnati

April 5, 2013

By

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B.S. Michigan State University, 2010

Committee Chair: Dr. Robert J. Hopkin, MD
Abstract

Introduction: Duchenne / Becker muscular dystrophy (DBMD) is an x-linked condition with a wide variation of clinical presentation due to specific gene mutations and the gender of the affected individual. For families of the most severely affected male patients, care needs, natural history, and potential interventions are paramount. In contrast, reproductive risks may be important for less severely affected individuals as in the case of Becker phenotype or DBMD carrier females. The published literature has suggested the caregiver burden and poor prognosis of DBMD has an impact on the biological family as a whole. Additionally, published literature suggests a high disruption rate of adoptions that involve a child with special needs. However, the literature does not currently describe the role of genetic counselors in addressing the needs of families who have adopted a child with DBMD.

Purpose: The purpose of this study was to determine the needs of adoptive families with sons diagnosed with DBMD, and how genetic counseling could be tailored to improve this population’s experience.

Methods: Participants were adoptive parents of males who were under age 18 and had a DBMD Diagnosis. They were recruited through Cincinnati Children’s Hospital Medical Center or Duchenne Connect. Semi-structured qualitative interviews were conducted by telephone with use of an interview guide. The interview content was analyzed for recurrent themes using NVivo© software. These themes were organized into categories to summarize the findings.

Results: Thirteen adoptive parents were interviewed. Their needs, relative to the diagnosis of DBMD, genetic counseling, and the genetics information, were not specific to adoptive families. In addition to the anticipated themes, 2 adoption specific points were described. Parents of adopted children with DBMD place importance on communicating the diagnostic implication of DBMD to the biological parents. Second, adoptive parents who questioned their ability to raise a child with special needs prior to the adoption re-considered their negative preconception.
**Conclusion:** This study indicates that adoptive parents need psychosocial support in adjusting to the DBMD diagnosis; although this is not specific to adoptive parents, the parents also indicated that the diagnosis caused a short-term reconsideration of whether the adoption was the right choice. Interestingly, adoptive parents indicated a strong and unexpected desire for recurrence risk information and placed importance on communicating this risk with the biological parents. Due to the frequent inclusion of genetic counselors in diagnosing DBMD, an awareness of the adoption-specific and non-specific informational needs are important in tailoring a genetic counseling session to best meet an adoptive parent’s needs.
Acknowledgements

I would like to acknowledge all of the hard work and continuous input of my research committee: Martha Walker, M. S., CGC, Robert J. Hopkin, MD, and Holly Peay, M.S., CGC. I would also like to thank Medical/Doctoral student Julie Lander, B.S. for her input on my results and the intercoder reliability. Additionally, my thanks go to Duchenne Connect, Brenda Wong, M.D. and the CCHMC Neuromuscular Care Center for allowing me to recruit from their respective databases, and to Jean Bange for performing the CCHMC database search.
# Table of Contents

<table>
<thead>
<tr>
<th>I. Abstract</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>II. Acknowledgements</td>
<td>5</td>
</tr>
<tr>
<td>III. List of tables</td>
<td>7</td>
</tr>
<tr>
<td>IV. Introduction</td>
<td>8</td>
</tr>
<tr>
<td>V. Methods</td>
<td>9</td>
</tr>
<tr>
<td>VI. Results</td>
<td>11</td>
</tr>
<tr>
<td>VII. Discussion</td>
<td>19</td>
</tr>
<tr>
<td>VIII. Conclusion</td>
<td>22</td>
</tr>
<tr>
<td>IX. References</td>
<td>23</td>
</tr>
<tr>
<td>X. Tables</td>
<td>24</td>
</tr>
<tr>
<td>XI. Figures</td>
<td>26</td>
</tr>
<tr>
<td>XII. Appendix</td>
<td>27</td>
</tr>
</tbody>
</table>
List of Tables and Supplementary Material

<table>
<thead>
<tr>
<th>I.</th>
<th>Table 1: Demographics and quantitative data</th>
<th>21</th>
</tr>
</thead>
<tbody>
<tr>
<td>II.</td>
<td>Table 2: Intercoder Reliability</td>
<td>23</td>
</tr>
<tr>
<td>III.</td>
<td>Figure 1 and 2: Descriptive Data</td>
<td>24</td>
</tr>
</tbody>
</table>
Introduction

Recent advances in technology have led to an abundance of genetic information to be explained to parents of a child with a genetic condition. The time of diagnosis is often a crisis situation for parents, and follow-up clinic visits are also associated with emotional distress (Lehmann, Speight, & Kerzin-Storrar, 2011). Crisis situations and emotional distress can affect parents’ ability to comprehend complex medical and genetic information. The explanation of genetic information must be tailored to individual families in order to best serve them. Trained in both genetics and supportive counseling, genetic counselors are well-suited for taking on this responsibility (Burns & Reiser, 1992). A genetic counselor’s scope of practice can include participation in the medical management of individuals with genetic conditions, helping people understand and adapt to the medical, psychological and familial implications of genetic disease, providing recurrence risk assessment, promoting informed decision-making, facilitating genetic testing, and making referrals to appropriate psycho-social resources (Uhlmann, Schuette, & Yashar, 2009). For patients diagnosed with X-linked genetic disorders such as Duchenne or Becker muscular dystrophy (DBMD), the genetic counselor or diagnosing physician has the important task of discussing the reproductive and personal medical implications for affected individuals as well as female relatives who carry a DMD gene mutation (Bushby et al., 2010).

Certain considerations are necessary for alternative family structures such as adoptive families (Lehmann et al., 2011),(Burns & Reiser, 1992). For example, adoptive parents may be less interested in knowing the recurrence risk of a genetic disease because they presumably do not carry the mutation.

Nevertheless, many studies are currently discovering mutation specific-therapies as well as phenotype-genotype correlations for a prognostic indicators of DBMD (Beggs et al., 1991). Additionally, approaches for informing family members(including biological parents) of the future reproductive risks and emotional support resources have been shown to be of use to parents (Bushby et al., 2010). These topics are not adoption specific and have been found to be of use in biological families with a child.
diagnosed with other neuromuscular genetic diagnoses (Meldrum, Scott, & Swoboda, 2007). A thorough literature review through google scholar®, Scopus®, pub med®, and the electronic scientific journal databases of both University of Cincinnati and CCHMC yielded no published material specific to adoptive family structures and DBMD. Most studies involving adopting children with a genetic disorder focus on genetic training within the social work field (Burns & Reiser, 1992) or genetic counseling in the prenatal/ perinatal setting (Perry & Henry, 2010; Taylor, Mapp, Boutte-Queen, & Erich, 2010).

Materials and Methods

This is a qualitative study developed to describe the genetic counseling needs and diagnostic experiences of parents who adopted a child diagnosed with DBMD. DBMD was chosen because it follows X linked inheritance, yet the new mutation rate is high (Alcantara, 1999). Thus, biologic parents may or may not know their son’s DBMD risk at the time an adoption plan is made. The areas of focus were the psychosocial concerns related to the DBMD diagnosis, the parental emotions associated with the diagnosis and adoption, and parental adaptation to the diagnosis over time. An anticipated outcome of the study is information about how genetic counselors can help adoptive parents adjust to the diagnosis of DBMD. Qualitative, semi-structured telephone interviews were used. The data were then transcribed and analyzed to delineate recurring themes.

A grounded-theory approach was used to understand the emergent themes from the parent’s descriptions of their diagnostic process, experiences or expectations of genetic counseling, and how they adapted to the diagnosis over time (Beeson, 1997; Grubs & Piantanida, 2010; McAllister, 2001). The semi-structured interview guide is available as (Appendix A). Unscripted follow-up questions were based on the responses from each individual participant and evoked conversation flow. The interview was designed to first obtain demographic information about each participant, followed by information on the process of his or her son obtaining a diagnosis. Then the level of interest in genetic counseling and how genetic counseling could be used was investigated. The genetic counseling specific information
was branched into two different question sets based on whether the participant had received genetic counseling or services. Genetic services were defined for this study as a consultation with a geneticist or genetic counselor either in-person or over the telephone.

The questions included questions on themes related to: 1) needs and expectations relative to receiving a diagnosis of DBMD, 2) psychosocial concerns about the diagnosis in relation to the adoption, 3) parental adaption to the diagnosis over time, 4) interest or desire for genetic counseling (either retrospective or hypothetical), and 5) expectations for the genetic counseling appointment.

The inclusion criteria for participants were parents over the age of 18 who had adopted a male child diagnosed with DBMD. This child was required to be currently living, have a confirmed diagnosis of DBMD, and under the age of 18 years at the time of the interview. Parents were excluded from this study if their child was older than age 18 or they had an unofficial adoption, such as fostering their child. Participants were recruited through two resources:

1) The patient database at the Neuromuscular Care Center at Cincinnati Children’s Hospital Medical Center (CCHMC) and the EPIC electronic medical record were queried for families meeting the criteria. Letters with a description of the study were mailed to these parents. Non-respondents were telephoned two weeks later. Families with an invitation to schedule an interview

2) Duchenne Connect (DC), a registry affiliated with Parent Project Muscular Dystrophy (PPMD) posted an announcement of the study on its website (www.duchenneconnect.org). Interested individuals contacted the DC staff or the primary investigator (PI) for further information.

The interview was piloted once to assess the understandability of the questions as well as whether the questions elicited the participant’s experiences. Piloting involved an interview between the PI and the biological parent of a young adult with DMD. After the pilot interview and input from experts in DMBD, interested individuals were contacted and a telephone interview was scheduled. Verbal agreement and consent to participate were obtained upon initiation of the interview telephone call. All
interviews were recorded with a digital voice recorder. The interview content was transcribed, personal identifiers removed, and transcripts were then exported to NVivo© software for analysis.

Analysis was performed by recognizing recurrent question responses and assigning descriptive codes for similar responses by using the N*Vivo© software program. A second individual was trained in N*Vivo© and provided a second analysis by assigning codes for recurrent responses in three transcripts to assess the reliability and the consistency of the response codes. Where codes of responses differed between the two analyses, a consensus for coding was reached. The Intercoder agreement, in the form of intercoder reliability (ICR) was measured (table 2). The consensus coding was then used for the thematic analysis.

This study received “exempt” status from the Institutional Review Boards at CCHMC and the University of Cincinnati College of Medicine.

Results

The CCHMC database yielded 23 patients meeting eligibility requirements. Six of the parents replied to the invitation letter and were interviewed. Eight parents responded to the DC posting: One was excluded because of ineligibility; seven were interviewed. Participant age range was 34-57 years, and their sons were between 3 and 14 years of age at the time of the interview. Age at diagnosis ranged from prenatal to 8 years old, with a median of 3 years and 9 months of age. Two participants knew about the diagnosis of DBMD prior to the adoption, and eleven received this diagnosis after the adoption had already been legally completed. Table 1 provides an overview of the participants and their sons. The length of the interviews ranged from 35-62 minutes.

The interviews included three primary topics: (1) perceptions and impact of how the DBMB diagnosis was delivered; (2) the adjustment to the diagnosis over time; and (3) interest in and use of genetics information. Selected quotations from the interview participants are included within each theme to illustrate representative participant’s views.
Perceptions and impact of how the DBMD diagnosis was delivered

The interviewer asked questions regarding the diagnosis delivery and whether anything specific could be done to make the experience less difficult or distressing. All participants described feelings of sadness at the time of the diagnosis. Four parents noted that it was hard to accept the diagnosis with their child being asymptomatic and not visibly affected. This resulted in denial for a period of time. As participant E stated,

“Well when we found out, [son’s name removed] wasn’t having any symptoms. So just so you know I think when a lot of people find out they are already dealing with symptoms. So when we found out we didn’t have to deal with the actual disease. Which I think makes a huge difference... well we could only deal with it emotionally without dealing with the symptoms. It was just um... I mean honestly I just grieved for like a whole year. It was just sad.” (Participant E)

Anger was noted by four participants, two of whom had an apparently unpleasant experience of learning their child’s DBMD diagnosis by phone when they were in a public setting. Four participants seemed displeased with the delivery of the diagnosis because of pessimistic phrases such as “he is not going to live,” or no referrals or helpful recommendations were provided. Participant I stated,

“He said he could live another twenty years... and that didn’t make us feel any better. And then he took his business card, asked us if we had internet access at home, then he wrote Duchenne Muscular Dystrophy on the back of the card and told us to look it up on the internet.”

(Participant I)

Participant K made a suggestion regarding the delivery:

“I think it would be probably helpful to parents, especially [those] receiving an initial diagnosis ... [to inform parents that] they are still kids and they will still do wonderful things and there is always hope and it doesn’t have to be all bad all
Later this participant mentioned,

“[the doctor] essentially told me to go home and enjoy him until he can’t walk anymore....” (Participant K)

Additionally, many of the interviewees described the portrayal of the diagnosis as too harsh, negatively phrased, or portrayed in an unsupportive manner by the physician. Participant C shared her experience:

“... in retrospect, it was because he just didn’t [want] to say I don’t know. He was just very pessimistic [and] gave us a very pessimistic outlook. He didn’t refer us to any one that was helpful and we did actually talk to the pediatrician afterwards and told him that he was horrifying to deal with because he was very detached.” (Participant C)

Some participants brought up their perfect diagnostic scenarios or what a medical professional could do better in delivering a diagnosis. Participant E described her ideal situation:

“Look in a perfect world, somebody would sit down with you and say your son has Duchenne Muscular dystrophy, here is the genetic testing review, here are the clinical trials that we are aware of that could potentially be useful to you.... here are the clinics that you could take your child to, here is the MDA,...”

(Participant E)

All thirteen participants mentioned some additional supports would be helpful for a physician to provide with the diagnosis. Two categories of information emerged: psychosocial/ coping resources and medical/informational resources. The majority of the participants utilized some type of psychosocial support at the time of the diagnosis, be it church, support groups, friends, or spouse. Five articulated that they would have liked to speak to another parent going through a similar situation
Suggestions were made for follow up visits, a road map for how to obtain referrals, and a comprehensive packet of information. These suggestions were made to aid in helping a parent to understand and comprehend the information.

**Adjustment to the diagnostic information over time**

Many participants described how their feelings about the diagnosis changed over time as they adapted and adjusted to having a child who was adopted and also affected with DBMD. Ten participants reported some positive change(s) in their emotions since the time of the diagnosis. They described deepening love for their son, acceptance of the diagnosis, hope for the future, and being glad that they had adopted their son and were providing a home and family for him. Four participants reported feeling that they were able to provide care for the child that would not have been possible without the adoption. An example of this was provided by participant C:

“So, our ... pediatrician at [clinic] told us that if [son’s name] was not adopted, once his diagnosis was confirmed in China, they would have stopped his care, they would have stopped feeding him... so of course we are glad because we have literally saved [son’s]’s life.” (Participant C)

Two participants said that the diagnostic information confirmed to them that adoption was the right choice. Participant E illustrated this by stating in the interview,

“I just feel so strongly and believe so strongly that this is just part of my life plan is to raise this little boy and I really I wouldn’t want any other little boy. He was meant for me and I just couldn’t love anybody as much as I love him...”

(Participant E)

In response to questions about how the diagnosis affected the parent/child relationship nine participants admitted to harboring negative feelings about the DBMD diagnosis and prognosis while maintaining a positive feeling about the child and their decision to adopt him. Participant I stated:
Well, I don’t think [any information] could strengthen our relationship any more than what it already is. And I don’t think there is anything that can weaken it either...The fact that he is adopted is... it’s a nonfactor for us. So ... I don’t think I don’t think it’s affected [our relationship with our son] at all.” (Participant I)

Some of these negative feelings were anger, grief, being overwhelmed with the diagnosis, or the sense of life not being fair. Most often these sentiments were in relationship to the progression and symptoms of DBMD rather than the adoption itself.

In contrast, two participants said that they questioned the adoption when they received the diagnosis; this was mostly related to being unsure in their ability to raise a child with DBMD. One of these participants received the diagnosis before the adoption was finalized; the other received the diagnosis after. Participant G shared

“I would say when we first got the information we had to go through discussions with me and my husband about is this what we really want... because we hadn’t adopted him yet.” (Participant G)

Five other participants mentioned they thought later about the questions on the adoption paperwork related to their willingness to adopt a child with special needs and their feelings currently versus prior to the adoption. Participant A shared how her perception of her caregiving ability changed:

“It makes me...second guess. Not too many people know this but when you go in for an adoption [the adoption staff] has a ton of paperwork they make you fill out and they ask you multiple times [if] you would be willing to adopt a special needs child. Well our answer was no, ...[and] we didn’t going in thinking that [we could care for a child with special needs].” (Participant A)

Interest in and use of genetic information

Three main themes emerged upon discussing the participants’ interest in the information
about DBMD and the molecular genetic testing results. In order of response frequency the themes were:
1) Parent’s interest in communicating the genetic information to the biological family (13 of 13),
2) Importance in receiving the genetic testing as a confirmation of the clinical DMBD diagnosis (12 of 13),
and 3) Parent’s interest in genetic information for mutation specific therapies or research (4 of 13).
Eleven of the 13 participants had received some type of clinical genetic services, and 2 of these 11 participants received the diagnosis prior to the adoption. All participants who received genetic services indicated that the information on DBMD natural history and medical management was important to them. This information helped them make informed decisions regarding the medical care of their child and gave the two participants who received the diagnosis prior the adoption the confidence to follow through with the adoption. To illustrate how the information aided her in decision to follow through with the adoption, participant G stated:

“I didn’t want to... make the decision strictly on the fact that we absolutely love this little boy. There is a lot more to it when you are talking about a Duchenne child and I don’t know that everybody is prepared to take on that medical need as time goes on. So uhm... I think giving us as much information as we can and then giving us an informed decision is probably one of the biggest things that was important to us.” (Participant G)

All 13 participants discussed their desire to communicate the DBMD diagnosis and either recurrence risk or carrier testing to the biologic relatives of their son. Nine participants had notified the biological family of the DBMD diagnosis. Four of the participants did not have the ability to contact the biological family of this diagnosis although two of them did make an attempt. Of those who could deliver this information, three individuals initiated contact due to health concerns for the biological mother due to her potential carrier status. Participant A shared her reasoning as

“...and for her own health because I had read that there were other issues that...”
she could possibly have down the road.” (Participant A)

Four individuals mentioned the importance of testing future children or alerting the birthmother for family planning purposes. Participant F said,

“I wanted to do it because... well... because of our love for her, our respect for her, and [the birthmother] had a daughter of childbearing age. And we wanted her to be aware hey... this can be passed on. We wanted her to let her know that there is genetic testing that is available for her daughter.” (Participant F)

Three felt that they had a moral obligation to pass on the information and two indicated the importance of contacting relatives specifically for testing purposes. One individual made contact with the birth mother to let her know that her son was still loved. Three had an open adoption/ongoing relationship with the birth mother.

Eleven of thirteen participants of the participants thought that discussing the molecular diagnostic information was useful. Of these, four discussed that they were interested in mutation-specific treatments and therapies, such as exon skipping clinical trials. Participant I explained,

“Well, I mean a lot of the treatments now are mutation specific so now that we know exactly what his mutation is and we know what research is possible and what research would maybe help him, the exon skipping is mutation specific so you need to know what the mutation is to know what to do that will help him.”

(Participant I)

Others mentioned that, because their son has a more rare mutation, there were few or no clinical trials for which he was eligible. This was a major frustration for all who reported that their son had a rare mutation. Participant M shared her experience:

“We are interested in it but there are not any available for him yet. So this is the first thing that we have available for us. He is having an actual biopsy done
so that will hopefully open more doors.” (Participant M)

Participant C also discussed this topic:

“We found out that [son’s name] actually has duplication, which is the more rare version, he has very long duplications, which you know makes it more difficult, quite frankly to treat, because you know you can’t use some of the drugs or the experimental drugs that you can use for the ones with skipping where they... try to ... carve out the parts of the gene that are correct. You can’t really do that with [son’s name] because with duplication every kid with a duplication is unique.” (Participant C)

Nine participants said that genetic and recurrence risk information was not applicable to them due to their adoptive family structure. Participant I said,

“Because we adopted him that the genetics factor, the [mutation] and all of that was where his issues lie, I really had never seen a huge reason and I could be wrong in what geneticists do or what [genetic counseling] actually is, but I figured that you know... we really didn’t need to spend a lot of time in the genetic end of it. It wasn’t our genetics.” (Participant I)

Three participants took this set of interview questions as an opportunity to state their allegiance to their children and their view that parenting of an adopted child is “exactly the same” as parenting a biologic child. Participant J, for example, stated:

“No. No see we feel the same way about our adoptions as my daughter who is pregnant with our grandchildren.” (Participant J)

Importantly, some participants discussed the impact of the genetic information on the emotions surrounding the adoption. Four participants stated that the genetic information had no impact on the adoption. As mentioned previously, five participants reconsidered aspects of the adoption such as
responses in the paperwork and two re-considered the adoption after learning the diagnosis. However, when asked how the genetic information gave them this perspective, all seven of these participants responded that although they had re-considered aspects of the adoption, they ultimately were glad that they had adopted their son.

Discussion

This study aimed to describe parents’ expectations and needs in a genetic counseling session relative to adopted children with a genetic diagnosis using DBMD as a model. More specifically, this study asked how genetic counseling could be tailored to best meet this population’s psychosocial and informational needs. The study yielded information not only on genetic counseling needs but how parents of adopted children with DBMD use genetic information, how the diagnosis impacts their views of the adoption retrospectively, and how the adjustment to the diagnosis over time can alter their feelings about their ability to raise a child with special needs. Additionally, the parents discussed resources that helped in the adaptation to the diagnosis, though these were generally not adoption-specific.

When asked about the interest and use of genetic information, while the participants uniformly responded that a genetics session is not a specific interest for them, they later indicated clear desire for specific information that would come from a genetic counseling session. Adoptive parents from this study mentioned many of the same uses for genetic information as biological parents of children with a neuromuscular diagnosis mentioned in a previous qualitative study assessing genetic counseling needs (Meldrum et al., 2007). Examples of this similar use of genetic information are: explaining genetic testing results, delivering the diagnosis to a child in a sensitive and age-appropriate manner, covering mutation type-specific therapies, and describing clinical trials. Adoptive parents also strongly valued psychological support to aid in adjusting to the DBMD diagnosis, which, in addition to the aforementioned informational needs, are all within the scope of genetic counseling practice. However, these topics are
not specific to adoptive families, and may be pertinent to any family with an individual affected by DBMD as noted in the two part study by Bushby et. al.

In addition to the typical information provided to biological parents, the parents in this study did consistently mention an adoption-specific use of genetic information. All thirteen parents reported strong interest in sharing the diagnosis with the biological family. Although some parents were not able to make contact with their son’s birth parents due to limitations with international adoptions, all expressed a desire to discuss the genetic impact for the biological relatives with the birth parents. Many parents also indicated that facilitating genetic testing of carrier status for the biologic parents was of interest to them.

Many parents mentioned that they were not given an explanation of what genetic counseling was upon receiving a referral or that it could provide information beyond recurrence risks. One parent described that she was unaware of what genetic counseling could provide and the session resulted in her not asking questions she had that were within the scope of genetic counseling practice. Diagnosing physicians need to be aware of the potential differences and similarities in the use of genetic information between adoptive and biologic family structures. As adoptive parents are often not aware of genetic counseling or what a session can provide them, it is important for the diagnosing physician to explain the referral and how the adoptive family can benefit from genetic counseling.

Clearly, the study suggests that the diagnosis has a large impact on the feelings surrounding a genetic diagnosis in relation to adoption. In fact, although all families in this study were happy with their decision to adopt, many families admitted to reconsidering the decision to adopt when they discovered the diagnosis. This appeared to be more due to lack of confidence in their ability to provide care than lack of love for the affected child. When disclosing a diagnosis of DBMD to a family who has adopted an affected child, attention needs to be paid to this issue of potential adoption disruption. Two parents also discussed that the DBMD diagnosis not only briefly caused disruption in their feelings of the adoption
but caused enough emotional strain that their relationship resulted in either divorce or separation. This is emphasized by other studies that have found a large adoption disruption rate when families realize their adopted child had a medical condition or special needs (Berry, 1990; Denbya, Alfordb, & Ayala, 2011; Marcenko & Smith, 1991).

Many parents remembered being asked about adopting a child with special needs on the initial adoption paperwork. Most indicated that they did not originally plan to adopt a child with special needs, and may have even avoided doing so at that time. However, all of these parents subsequently discovered that caring for their son with DBMD allowed them to realize that they could raise a child with a significant medical condition. Many believed that talking to a parent with a child with DBMD at a similar age as their own would have helped them cope with the diagnosis. This contact was reported as one of the most useful resources by these adopted parents.

A subset of parents also discussed that using adoption friendly language allowed them to feel more open within a medical setting. Although insensitive verbiage did not change their feelings about the adoption, it did make them question their ability to care for their adopted child. Statements which highlighted only the poor prognosis or quality of life delivered in a blunt or uncaring manner lead parents to become upset or depressed and subsequently feel ill-prepared to raise a child with DBMD. With the known increase in adoption disruption seen in cases of children with significant special or medical needs, it is important to provide a balanced portrayal of the DBMD diagnosis and the tools for adoptive parents to effectively manage their child’s medical requirements.

A limitation of this study is the potential for incomplete saturation of data. Many studies noted that although 12 participants can be sufficient, 15 is typically what is used for data saturation (Beeson, 1997; Hill et al., 2005). However, consistent themes across the interviews were obtained, demonstrating sufficient data saturation. With 13 participants, however, these results may not be generalizable to the general population of adopted parents of a son with DBMD, and further research could be considered.
Additional studies could include other conditions to document that the needs identified are applicable to a wider population of adoptive families.

**Conclusion**

Adoptive parents of males with DBMD need complete information regarding the disease and their child’s medical care needs at the time of diagnosis. The language and sensitivity with which the DBMD diagnosis is delivered is clearly important to these families. The adoptive parents reported a short-term disruption to their decision to adopt their child; additional psychological support may aid them in adjusting to the diagnosis. Adoptive parents are interested in genetic recurrence risk information as they are motivated to educate the biological family on the DBMD diagnosis, risks for future offspring of the biologic mother, and health risks for female DBMD gene mutation carriers. This study indicates that adoptive parents often receive genetic counseling as part of their child’s DBMD medical evaluation and that it would be helpful if a description of genetic counseling services was provided at the time of referral. Adoptive parents’ genetic counseling needs are similar to biologic parents’ needs but this study suggests that the genetic information is used differently.
References


Table 1: Description of Interview Participants

<table>
<thead>
<tr>
<th>Participant Descriptor</th>
<th>Total Number</th>
<th>Number from DC*</th>
<th>Number from CCHMC**</th>
</tr>
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<tbody>
<tr>
<td>Male Participants</td>
<td>2 (15%)</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Female Participants</td>
<td>11 (85%)</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Participants with child with DMD</td>
<td>12 (92%)</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Participants with child with BMD</td>
<td>1 (8%)</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Received diagnosis before adoption</td>
<td>2 (15%)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Received diagnosis after adoption</td>
<td>11(85%)</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Received diagnosis from pediatrician</td>
<td>5 (38%)</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Received diagnosis from neurologist</td>
<td>6 (46%)</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Received diagnosis from geneticist</td>
<td>1 (8%)</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Received diagnosis from social worker</td>
<td>1 (8%)</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>International Adoption</td>
<td>4 (31%)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Adoption within the United States</td>
<td>9 (69%)</td>
<td>5</td>
<td>4</td>
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* Duchenne Connect  
** Cincinnati Children’s Hospital Medical Center
Table 2: Intercoder Reliability

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Description of codes:

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<td>anyone in room when diagnosis was made</td>
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<td>AnyChgGC</td>
<td>would you change anything in the genetic counseling session</td>
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<td>CarGvrAsp</td>
<td>care-giver aspects</td>
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<tr>
<td>CtaftDx</td>
<td>who did you contact after the diagnosis was made</td>
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<tr>
<td>CurServ</td>
<td>services you are currently receiving</td>
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<td>feelings at initial diagnosis</td>
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<td>FeelpostDx</td>
<td>feelings altered over time after the diagnosis</td>
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<tr>
<td>GCimpdx</td>
<td>what was the impact of genetic counseling on the diagnosis</td>
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<tr>
<td>GCimpAdopt</td>
<td>how did genetic counseling impact the adoption decision</td>
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<td>GCple</td>
<td>what were you pleased with in a genetic counseling session</td>
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<tr>
<td>Infoport</td>
<td>how do you prefer to receive information</td>
</tr>
<tr>
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<td>hopes and expectations of genetic counseling</td>
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<td>age of interviewee</td>
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<td>resources used at diagnosis</td>
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<td>resources wished had at time of diagnosis</td>
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<td>what happened immediately after the diagnosis</td>
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<td>helpfulDx</td>
<td>what helped in adjusting to the diagnosis</td>
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<td>WhynoGC</td>
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Figure 1: Chart of participant description

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<td>Diagnosis (DMD/BMD)</td>
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<td>Diagnosis Before/After Adoption (Before/After)</td>
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<td>9</td>
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<tr>
<td>Respondants Recruited through</td>
<td>7</td>
<td>6</td>
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</table>

(Duchenne Connect/ Cincinnati Children’s Hospital Medical Center)

Figure 2: Chart of professional that delivered the diagnosis

Diagnosis delivered by:

- Pediatrician: 36%
- Geneticist: 7%
- Neurologist: 43%
- Social Worker: 7%
Appendices

Appendix A: Interview Guide: Yes Genetic Counseling

Appendix B: Interview Guide: No Genetic Counseling

Appendix C: Recruitment letter for CCHMC

Appendix D: Recruitment e-mail for PPMD
Appendix A: Interview Guide - Yes Genetic Counseling

Introduction: Hello, I am calling for (name of interviewee). My name is Amy Gladstone and I am a University of Cincinnati genetic counseling graduate student. I am in charge of the research study “Assessing the genetic counseling needs of parents who have adopted a child with Duchenne/Becker Muscular Dystrophy”. Is now still a good time to have the interview? Again, it should last about an hour. Just as a reminder, there are no right or wrong answers or feelings in response to these questions. If you feel upset or do not wish to answer a question, we can skip it. The interview questions may bring up strong feelings about the time of the diagnosis or the adoption. If you wish to discuss your feelings with a professional genetic counselor after the interview, I will provide you with contact information. I will first ask some basic questions about your child’s age and initial diagnosis, and then we will move onto the more personal part of the interview.

Ok (name of interviewee), let’s get started. (interviewer will respond with “Thank you” after each answer).

1. What is your age?
2. What is your gender?
3. What is the name of your adopted son?
4. Does (name of son) have duchenne or Becker muscular dystrophy?
5. What is the age of (name of son) currently?
6. Are you the legal guardian of your adopted son?
7. How old was (name of son) when he was diagnosed with Duchenne or Becker Muscular Dystrophy?
8. Please describe to me how the diagnosis was made for (name of son). **build off of what they say**
   a. Who gave you the diagnosis?
   b. What type of doctor made the diagnosis?
   c. Was anyone else in the room with you when the diagnosis was made?
   d. How useful was the molecular basis of the diagnosis to you?
9. Please describe the feelings you experienced on the day the diagnosis was made. Probe if not addressed:
a. Can you remember how you felt when the doctor told you the news?

b. Do you remember what you did after the appointment?

c. Did you talk to anyone after the diagnosis was made? Who did you talk to and what did you tell them?

10. Please describe the feelings you have experienced since the diagnosis. If not addressed probe:

a. Some parents can feel emotions such as guilt, regret, relief for getting an answer, anger, or other emotions. Could you describe emotions such as the ones mentioned that you felt?

11. What resources helped you the most after the diagnosis and how did you use them? Probe if unsure of definition of resources:

a. Some resources could be pamphlets, referrals, respite care facilities, support groups, etc.

12. What resources, if any, did you need but not know about when the diagnosis was made? Probe if unsure of what resources are

a. Some resources could be pamphlets, referrals, respite care facilities, support groups, etc.

13. Did you have the means to contact (name of son)’s biologic family about this diagnosis, and if so, why or why not did you choose to contact them?

a. How did you initiate this contact?

Branching question: Have you ever met with a genetic counselor or genetics doctor regarding (name of son)’s DBMD diagnosis? (if yes go to yes GC question set, if no go to no GC question set). Genetic counseling for a diagnosis like DBMD can have many elements. Some of these elements can be explaining the genetics of the condition, talking about research options, emotional support, reproductive options, recurrence risks, how the condition will affect someone, and referrals to other medical support people. Do you have any questions about what genetic counseling is before we continue (if no GC set)?

YES GC QUESTION SET

1. What do you remember about your experience with genetic counseling? Probe if not addressed:

   a. Were any of the following elements included in the session?

      i. Genetics of DBMD
ii. Research or clinical genetic testing options

iii. Research study options

iv. Emotional support

v. Reproductive options

vi. Recurrence risks

vii. Adoption specific information

viii. Symptoms of the disease

ix. Referrals to other medical support people

b. How did you feel in the genetic counseling session about the information covered and the sensitivity used by the genetic counselor?

c. How long ago was this session?

d. Would you change anything in the genetic counseling session that the genetic counselor did?

e. Was there anything you were particularly pleased or dissatisfied with in the genetic counseling session?

2. What were you hoping to get from genetic counseling?

a. Refer back to the description of counseling elements if unsure how to answer

3. How did genetic counseling affect your relationship with (son’s name)?

a. Did it strengthen or weaken your relationship? If so, which one and how so?

b. Why did you feel it did not affect your relationship with (name of son)?

4. This question pertains to the sensitivity of language used by medical staff. What were your experiences with adoption-friendly language during genetic counseling?

a. What emotions did the language you described make you feel?

5. In what ways, if any, did genetic counseling affect your feelings about the diagnosis?
a. Why did genetic counseling not change your feelings about the diagnosis?

b. Is there anything special that could be done around the time of the diagnosis and if so, what and how could health care providers do this?

6. In what ways, if any, did genetic counseling affect your feelings about the adoption?

a. Why did genetic counseling not affect your feelings about the adoption?

b. How do you wish someone could help with these feelings regarding the adoption and the diagnosis?

That finishes the interview. Is there anything you thought I would ask that I didn’t? Do you have questions about anything we talked about or the study in general? (Name of interviewee), thank you so much for taking the time for this interview. If this interview has brought up any strong feelings and you need to talk them through, you can contact Holly Peay at Holly Peay at 443-791-5927 to set up a time to discuss these feelings. Holly is a certified genetic counselor. Thank you again for taking the time to speak with me.
Appendix B: Interview Guide—No Genetic Counseling

Introduction: Hello, I am calling for (name of interviewee). My name is Amy Gladstone and I am a University of Cincinnati genetic counseling graduate student. I am in charge of the research study “Assessing the genetic counseling needs of parents who have adopted a child with Duchenne/Becker Muscular Dystrophy”. Is now still a good time to have the interview? Again, it should last about an hour. Just as a reminder, there are no right or wrong answers or feelings in response to these questions. If you feel upset or do not wish to answer a question, we can skip it. The interview questions may bring up strong feelings about the time of the diagnosis or the adoption. If you wish to discuss your feelings with a professional genetic counselor after the interview, I will provide you with contact information. I will first ask some basic questions about your child’s age and initial diagnosis, and then we will move onto the more personal part of the interview.

Ok (name of interviewee), let’s get started. (interviewer will respond with “Thank you” after each answer).

14. What is your age?
15. What is your gender?
16. What is the name of your adopted son?
17. Does (name of son) have duchenne or Becker muscular dystrophy?
18. What is the age of (name of son) currently?
19. Are you the legal guardian of your adopted son?
20. How old was (name of son) when he was diagnosed with Duchenne or Becker Muscular Dystrophy?
21. Please describe to me how the diagnosis was made for (name of son). **build off of what they say**
   a. Who gave you the diagnosis?
   b. What type of doctor made the diagnosis?
   c. Was anyone else in the room with you when the diagnosis was made?
   d. How useful was the molecular basis of the diagnosis to you?
22. Please describe the feelings you experienced on the day the diagnosis was made. Probe if not addressed:
a. Can you remember how you felt when the doctor told you the news?
b. Do you remember what you did after the appointment?
c. Did you talk to anyone after the diagnosis was made? Who did you talk to and what did you tell them?

23. Please describe the feelings you have experienced since the diagnosis. If not addressed probe:
a. Some parents can feel emotions such as guilt, regret, relief for getting an answer, anger, or other emotions. Could you describe emotions such as the ones mentioned that you felt?

24. What resources helped you the most after the diagnosis and how did you use them? Probe if unsure of definition of resources:
a. Some resources could be pamphlets, referrals, respite care facilities, support groups, etc.

25. What resources, if any, did you need but not know about when the diagnosis was made? Probe if unsure of what resources are:
a. Some resources could be pamphlets, referrals, respite care facilities, support groups, etc.

26. Did you have the means to contact (name of son)’s biologic family about this diagnosis, and if so, why or why not did you choose to contact them?
a. How did you initiate this contact?

Branching question: Have you ever met with a genetic counselor or genetics doctor regarding (name of son)’s DBMD diagnosis? (if yes go to yes GC question set, if no go to no GC question set). Genetic counseling for a diagnosis like DBMD can have many elements. Some of these elements can be explaining the genetics of the condition, talking about research options, emotional support, reproductive options, recurrence risks, how the condition will affect someone, and referrals to other medical support people. Do you have any questions about what genetic counseling is before we continue (if no GC set)?

NO GC VISIT QUESTION SET

1. At the time the diagnosis was made, what would you hope to get from genetic counseling based on the following description:
Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates:
• Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence
• Education about inheritance, testing, management, prevention, resources and research.
• Counseling to promote informed choices and adaptation to the risk or condition.
• Genetic counselors also provide supportive counseling to families, serve as patient advocates and refer individuals and families to community or state support services.

a. List some elements or options that may have been ideally included in the session:

a. Genetics of DBMD
b. Research or clinical genetic testing
c. Research study options
d. Emotional support
e. Reproductive options
f. Recurrence risks
g. Adoption specific information
h. Symptoms of the disease
i. Referrals to other medical support people

b. How would you expect to feel in a genetic counseling session given the wide variety of information that genetic counseling can provide?

c. Is there support that you could have received at the time of the diagnosis that could have made it any less difficult?

d. Is there anything you would expect to be dissatisfied or satisfied about in a potential genetic counseling session?

2. What needs do you currently have that could be addressed by genetic counseling?

3. Please provide the reasons why you have not had genetic counseling.

a. Was genetic counseling not available to you or not offered?

b. Were you aware of genetic counseling before this research study?
c. Why did you feel as though genetic counseling would not be helpful?

4. This question pertains to the sensitivity of language used by the medical staff: what have been you experiences with adoption-friendly language during health care visits with (name of son)?
   a. Was there an experience where a medical professional was not aware of the adoption?
   b. Has anyone ever treated you or (name of son) differently within the medical field due to the adoption?

5. Do you feel genetic counseling would change your feelings on the diagnosis, and if so how? I can read to you again what genetic counseling is if it would help answer this question for you.
   a. In what ways might this type of appointment change how you would think or feel about the diagnosis?
   b. Would you expect your feelings about the diagnosis change or do you expect to feel the same regardless of what information is presented or how it is presented?
   c. Is there anything special that could be done around the time of the diagnosis, if so what and how could health care providers do this?

6. Do you feel genetic counseling would change your feelings on the adoption at all, and if so, how?
   a. In some individuals they have felt some regret or very overwhelmed about everything they were going through
   b. Is there any information that could be given to you that would make you alter your feelings about the adoption?
   c. Is there any reason why no information given would alter your feelings surrounding the adoption?
   d. How do you wish someone could help with these feelings regarding the adoption and the diagnosis?

That finishes up the interview. Is there anything you thought I would ask that I didn’t? Do you have any questions about anything we talked about or the study in general? Well, (name of interviewee), thank you so much for taking the time to participate in this interview. If this interview has brought up any strong feelings and you need to talk them through, you can call Holly Peay, a certified genetic counselor, at 443-791-5927 during business hours.
Appendix C: Recruitment letter for CCHMC

Dear _______________,

You are being invited to take part in a research study through Cincinnati Children’s Hospital Medical Center (CCHMC) Neuromuscular Care Center and the University of Cincinnati. Our records show that you have received care through the CCHMC Neuromuscular Care Center for your adopted son’s diagnosis of either Becker or Duchenne Muscular Dystrophy. The title of this study is “Assessing the Genetic Counseling Needs of Parents who have Adopted a Child with Duchenne or Becker Muscular Dystrophy”. The purpose of this study is to learn how to better care for adopted sons with a diagnosis of either Becker or Duchenne Muscular Dystrophy in a Genetic Counseling Session. As a parent of a child with Duchenne or Becker Muscular Dystrophy you will be asked open ended questions on the telephone to learn about your experiences with genetic counseling.

This study will be done through open-ended telephone interviews. These interviews will be recorded electronically and password protected. The interview will be destroyed after the data is analyzed and coded. In order to be a part of the study, you must be a parent of a legally adopted child under the age of 18 with a diagnosis of Duchenne or Becker Muscular Dystrophy. You must have a telephone and be English speaking.

Your answers to these questions will aid in helping us to improve the care in genetic counseling for children who are adopted and have a serious genetic condition. Risks involved in this survey are limited to uncomfortable feelings and accidental disclosure of personal information. The accidental disclosure of such information will be kept in a locked area and all electronic material will be password protected. Once the data is analyzed it will be coded and not linked to your child’s name or information. Contact information will be provided for a trained support person through Parent Project Muscular Dystrophy in the case of uncomfortable feelings brought up during the interview.

You are able to choose whether or not to take part in this study. Choosing to not take part will not in any way affect your child’s care here at the Neuromuscular Clinic. Should you choose to do the interview, please contact me at either 248-217-6100 or at amy.gladstone@cchmc.org. We can then set up a time convenient for you to do the interview. The interview will take approximately 45-60 minutes.

Thank you for your consideration.

Amy Gladstone, B.S.                     Dr. Brenda Wong, MD, MBBS
Genetic Counseling Graduate Student     Director of Neuromuscular Care Center
Cincinnati Children’s Hospital Medical Center     Cincinnati Children’s Hospital Medical Center
University of Cincinnati
Dear Mr. or Ms. __________________________,

Amy Gladstone, a genetic counseling graduate student at Cincinnati Children’s Hospital Medical Center (CCHMC) and University of Cincinnati, is conducting a research study to learn the needs of parents who have adopted a child with Duchenne or Becker Muscular Dystrophy (DBMD). This study is looking at the parent’s experiences and needs in genetic counseling.

This study will help us learn how to better care for children who are adopted and have a diagnosis of DBMD. The overall goal is to seek how to best care for adopted children with a serious genetic condition within a genetic counseling session. This study is open to parents who have legally adopted a child under 18 who currently has a diagnosis of DBMD. The parents must be English speaking and have access to a telephone. You do not need to have genetic counseling in order to take part in this study.

Taking part in this study involves a telephone interview that will last up to 60 minutes. The interview will be comprised of information about your son and his diagnosis as well as open-ended questions regarding your personal experience with genetic counseling. If you have not had genetic counseling, the interview will ask about your thoughts and needs for a potential genetic counseling session. The potential risks for this survey are minimal, but may include becoming emotionally upset or uncomfortable because of the questions asked in this survey. Due to this reason, a contact number will be provided to all participants for a support person from the Parent Project Muscular Dystrophy.

Should you choose to do the interview, please contact Holly Peay at holly@parentprojectmd.org or 443-791-5927 or you can contact investigator Amy Gladstone at amy.gladstone@cchmc.org or 248-217-6100. We can then set up a time convenient for you to do the interview. The interview will take approximately 45-60 minutes.

Thank you for your consideration.

Amy Gladstone, B.S.          Holly Peay, M.S. CGC
Genetic Counseling Graduate Student  Senior Director, Education and Outreach
Cincinnati Children’s Hospital Medical Center  Parent Project Muscular Dystrophy
University of Cincinnati