Parents’ perspectives on coping with Duchenne muscular dystrophy

C. L. Webb
Duquesne University, Pittsburgh, PA, USA
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Abstract

Background  The author, who has a grown son with Duchenne Muscular Dystrophy (DMD), has personally experienced a lack of available information for parents about coping with DMD. Therefore, as a longtime personal goal, she developed this study to address that lack of information.

Methods  Fifteen semi-structured interviews were conducted with 23 parents (n = 7 with both parents; n = 1 with two sisters; n = 6 with mothers only; n = 1 with father only). The purpose of the interviews was to examine the strategies parents use to cope when their sons have DMD. The interviews were conducted in 12 states, taped and transcribed.

Results  Grounded theory analysis of the interview data indicated the willingness of these parents to share information to empower others like themselves.

Conclusions  Parents want to be heard and valued as experts on DMD by medical and other professionals who interact with their sons. In addition, they want to proactively participate in their sons’ lives and to encourage other parents to do the same.

Introduction

Duchenne Muscular Dystrophy (DMD) is the second most common genetic disorder in humans. It is an X-linked recessive disorder, occurring in approximately 1 in 3500 male births (Cwik & Brooke 1996; Billard et al. 1998), and in about 1 in 50 000 000 female births (Pearson & van Ommen 1984). In an X-linked recessive disorder, the mutation which leads to the disorder is found in a gene on one of the X, or female chromosomes (Nicholson et al. 1993; Cwik & Brooke 1996). Females with a mutant X chromosome will not have DMD, but they will be carriers of the disorder. If their mutant X chromosome pairs with a Y chromosome producing a male, the boy will have DMD. This accounts for about 70% of DMD inheritances. Another 30% occur owing to a genetic mutation in the child (Parent Project Muscular Dystrophy 2000). Those very rare females who have DMD are believed to either carry mutant genes on both X chromosomes, or have an inactivated healthy X chromosome (Pearson & van Ommen 1984).

Duchenne Muscular Dystrophy is caused by the lack of the protein dystrophin that affects the skeletal muscles, leading to damage and eventual death of muscle cells. This leads to progressive muscle wasting, which eventually results in severe debilitation (Cwik & Brooke 1996). At this time, there is no cure and death often occurs owing to respiratory or cardiac failure in the late teens (Brooke et al. 1989). However, life expectancy is rising, probably owing to proactive care and more aggressive treatments. Although DMD is present from conception, boys with this disorder manifest symptoms such as waddling gait, toe walking, overdeveloped calves, and difficulty rising from the floor after they begin to walk (Cwik & Brooke 1996; Ivory 1998; Porter et al. 2001).
The diagnosis of DMD presents parents with many challenges. Mothers, in particular, have the added burden of knowing that they may be the unwitting carriers of the mutation responsible for the disorder. Therefore, as the disease progresses, mothers may develop an attitude of self-blame (Rubin 1987). Both parents may react with feelings of disbelief, denial, anger, anguish, anxiety, guilt (Buchanan et al. 1979; Rubin 1987; DMD Forum 2001) fear, confusion, powerlessness, rejection (DMD Forum 2001), and parent/child-related stress (Beresford 1994).

Studies based on coping skills of parents whose children have disabilities, although scant, add valuable information to the research literature. Beresford (1994) suggested that coping skills studies have greater implications for understanding and improving ways to help. She concluded that a consistent finding in both qualitative and quantitative studies is the usefulness of active coping strategies.

Bregman (1980) lived with each of six families whose children had progressive neuromuscular diseases for four days and nights to observe their coping strategies. Her findings illustrated the variety of problems and difficulties parents face as they care for their children with disabilities. Four types of coping strategies emerged from Bregman’s observations. Participants in the present study have corroborated those results as indicated below:

- Families focused on the present with a ‘one day at a time’ philosophy.
  The only way I can get through this mentally and keep my sanity is just to do it one day at a time.
- Families attempted to live as normal a life as possible.
  We are in the process of moving across town to be close to our son’s school. We want him to be in that neighbourhood and have just as normal a life as possible, stressing relationships with others.
- Families reduced the risk of crises by having a proactive attitude regarding the care and services for the child’s condition.
  Be very proactive. Keep your son walking as long as possible. When he can’t walk any-
behaviours in social interactions than to the physical manifestations of DMD.

Helm et al. (1998) conducted a qualitative study involving 10 mothers who received a prenatal diagnosis of Down syndrome. Particularly useful were the suggestions the mothers made to medical professionals concerning the supports they most valued. The following suggestions are appropriate for all types of disabilities and, indeed, were similar to those made in the present study.

**Advice to medical professionals**

- Make sure parents understand all prenatal tests.
- Give the diagnosis in person to both parents at the same time.
- Do not make assumptions or judgements about the parents’ decisions.
- Give non-judgemental information on all options.
- Give up-to-date printed material on the particular disability.
- Make referrals to appropriate sources of support.
- Present the diagnosis in a positive manner.
- Understand that parents may react adversely to the diagnosis and be prepared to recognize their feelings of loss.

In a study reported by Scorgie and Sobsey (2000), 15 parents of children with disabilities were interviewed about significant and positive changes (transformations) they made in their lives after their child’s diagnosis. Parents should be aware that most families of children with disabilities are able to cope effectively, and many also report life-changing benefits.

Parents believe it is important that schools as well as families provide realistic expectations, modelling, informal teaching, structure, support and reinforcement to children with DMD. Schools must work with parents to ensure that these children have successful academic and social experiences in the school setting (Mearig 1992; Strong & Sandoval 1999).

As these findings indicate, parents of children with disabilities have taken on a more proactive and vocal coping role in the last 25 years. Buchanan et al. (1979) reported that parents used overprotection, lack of child discipline, and even magical thinking coping skills. Holroyd and Guthrie (1986) found that parents were pessimistic about outcomes related to DMD, had negative feelings toward their children, and reported chronic emotional stress.

In contrast, Beresford (1994) suggested that studies on parent coping skills have implications for understanding disabilities and developing active coping strategies. Bregman (1980) reported that parents face a variety of problems as they care for their children with DMD. She discussed four coping strategies that both the participants in her study and those in the present study have found to be effective. Lastly, Scorgie and Sobsey (2000) described significant and positive changes (transformations) made by parents after their children were diagnosed with disabilities.

**Methodology**

**Selection of participants**

The sample was selected from volunteer participants recruited by posting a request on two Internet sites for parents of children with DMD. At the annual Parent Project Muscular Dystrophy (PPMD) Conference in 2001, the author discussed the future study and formally requested volunteer participants. Such methods enabled the author to network and find additional volunteers so that the sample represented a broad base of participants. The final selection of 15 families (culled from a possible 31 volunteers) was based on the age of the boys in the study, family demographics such as number of sons with DMD and geographical location (See Table 1).

**Data collection**

Individual semi-structured in-depth interviews (lasting from one-two hours) were conducted and audio-taped with 16 families [one father, seven mothers (two who were sisters), and seven sets of parents] to gather the data. Throughout the taping, the interviewer rephrased questions or asked the respondents to elaborate as a means of checking
for understanding, accuracy, and verification. The interviewer also made comprehensive notes after each interview to assist with later data analysis. The individual family interviews were conducted in the parents’ homes, an office, a restaurant, and a meeting room in a public library. The apparatuses used were a tape recorder to record interviews for later transcription and analysis and a list of sample questions developed by the author (See Appendix A). The sample list of questions was used as a guide, but actual interview questions developed from the statements and responses made by the families as the interviews progressed. This allowed the researcher to gather additional data to support and corroborate her findings.

Data analysis
An independent professional transcribed the tapes, verbatim, to allow for data analysis. The author analysed the data using grounded theory to make the information gathered comprehensible to those who were studied, those who work with persons with disabilities, and others who are interested in the particular phenomenon. Grounded theory, originated by Glaser and Strauss (1967), allows the researcher to develop a theory, which comes from, and is verified by the collected data. Grounded theory is composed of several steps that must be done concurrently throughout the study. Constant comparative analysis (Glaser 1994) consisted of open, axial, and selective coding to find patterns, relationships and themes (Mostyn 1985). According to Bogdan and Biklen (1998), Punch (1998), and Strauss (1987) there are three types of coding. They are:

1. **Open coding**, which is the initial coding. Its purpose is to produce concepts that fit the data thereby ‘opening up’ the inquiry (see Appendix B).
2. **Axial coding**. In axial coding, the researcher codes around single interconnected categories (See Appendix C).
3. **Selective coding**. At this stage of coding, the axial codes are examined to select the themes supported by the data.

Coding and memoing were used simultaneously throughout the data collection. During each stage of coding, ideas that occurred to the researcher were recorded as memos. The material was first open coded by words or phrases based on units of data. The open codes were written in the left hand margin next to the appropriate units of data. The open codes in the interviews were narrowed down into axial codes. During this process, each open code, axial code and memo was entered into a

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M, mother; F, father; S, son; D, daughter.
loose-leaf Concept Notebook (Mostyn 1985) for ease in compiling memos for each concept, organizing the data, and providing structure for the final report (Table 2).

A modified version of the cut-up-and-put-in-folders method (Bogdan & Biklen 1998) was selected over computer software to complete the analysis. The modified cut-and-file method consisted of (i) underlining the material in the transcripts that answered each of the original research questions; (ii) making a separate file folder for each question; (iii) cutting the sections of the manuscripts that answered each question into strips; (iv) preparing a topic outline based on the answers; (v) sorting and storing the strips by topic, and (vi) placing them in the appropriate folders pending analysis. As the synthesized report of the data was written, the author referred to and documented the results based on the material in each folder.

### Results

From the Grounded Theory coding process, the coping themes that emerged were Genetics, Diagnosis, Reactions to the Diagnosis, Treatment, Equipment and School Issues.

#### Theme 1: genetics

Duchenne Muscular Dystrophy is a disorder that is caused by a genetic defect on the X-chromosome. At one time, geneticists believed that DMD could only be inherited through a genetic mutation passed from one female carrier to another. Geneticists know that this type of inheritance accounts for only 30% of DMD cases. Other DMD inheritances are due to either an original genetic mutation in mothers (40%) or sons (30%) (Parent Project Muscular Dystrophy 2000). For this reason, it is common practice to test mothers, siblings, and maternal relatives of boys who are diagnosed. When my son was diagnosed, my mother, two sisters, and I were given blood tests called Creatine Kinase (CPK or CK) tests. Creatine Kinase is an important enzyme found in muscle fibres. With female carriers and boys who have DMD, CK leaks out of the muscle fibres so that large amounts of it are found in the blood serum. In young boys, CK ratios may be anywhere from five times to 100 times greater than normal (less than 200) (Cwik & Brooke 1996; Morris 2001). My daughter, born two years later, was also tested. None of us had elevated serum counts. Based on no family history of DMD and the CPK results, it appears that my son may have an original genetic mutation.

Two other diagnostic tests are muscle biopsies and DNA analysis. In the former, doctors take a sample of muscle, usually from the thigh. Microscopic examination of the muscle reveals variable fibre size, rounded muscle fibres, dead muscle cells, immune system response to infection, and scar tissue (Cwik & Brooke 1996, http://www.op.net/~wgs/dmd/dmdgloss.htm). DNA analysis of a blood sample has been developed since the discovery of the gene responsible for DMD in 1986, and the discovery of the missing muscle protein, dystrophin, in 1987 (Bartlett et al. 1992; Ivory 1998). Mutations in the DMD gene

**Table 2.** Sample concept notebook page ‘medical personnel’

| Father 15: | My brother a doctor. Suggested testing because of motor delays when our son was two. Led to early diagnosis. Diagnosis was accompanied by an understanding and knowledgeable family member. |
| My reaction: | My son was diagnosed at age 3½, after a physical therapist friend suggested that he be tested. Diagnosis was ‘to the point’ and painful. Doctor was unable/unwilling to provide understanding. Left my husband and me alone in strange and hurting new world of DMD. |
| Mother 02: | Being nurse made experience with doctors easier. |
| My reaction: | Noticed son tip-toeing and falling a lot. Doctor said she was just an overprotective mother. |
| Father 07: | Muscles were pronounced like wrestler. Tip-toed, was pigeon-toed, and had trouble climbing stairs. Doctor said he would outgrow it. |
| My reaction: | My son also had pronounced muscles in his legs. When he was four, shortly after diagnosis, a friend commented on how popular he would be with girls because he had such a nice build. The irony made it difficult not to cry. |
| Mother 08: | Son saw different doctor every time she took him in. She would comment to doctors about his abilities compared to younger children she had in day care but none of the doctors did anything about complaints. When son was finally tested, took a year to get the results. |
| My reaction: | My son received his diagnosis at Walter Reed Army Hospital in Washington, DC. At Walter Reed, they deadened the wrong leg for the muscle biopsy. As a result, the procedure was extremely painful and terrifying. |
lead to dystrophin deficiency, which is the cause of DMD (Tkatchenko et al. 2000). Through DNA analysis, it can be seen that boys with DMD have dystrophin in only about 1% of their muscle fibres (Cwik & Brooke 1996). There are 79 protein-coding sequences called exons needed for the production of dystrophin. In such a large gene, there are several types of mutations that can occur. Most of the mutations are deletions and duplications. The numbers of such mutations vary from 65% of cases (Parent Project Muscular Dystrophy 2000) to 81.5% of male cases (Nicholson et al. 1993). In addition, Nicholson et al. (1993) found that only one female case (out of a total of six) was due to a deletion. About 30–40% of the mutations are point mutations, which add, delete, or substitute a single block of DNA or RNA (Parent Project Muscular Dystrophy 2000).

Theme 2: diagnosis

In coping with DMD, the first tough issue that parents face is the diagnosis. Families in this study described atypical physical signs and behaviours before the diagnosis such as late onset of walking, tip-toeing, frequent falling, trouble climbing stairs, tiring after mild exertion, rising from the floor with hand support (Gower Manoeuvre), and unusually pronounced calf muscles. Several parents were frustrated by an initial inability to convince the doctors there was a problem.

When our son was about a year old, we noticed there was something wrong so I took him to my basic physician and he said, ‘there’s nothing wrong with him, you’re just an overprotective mother’.

As the above comment indicates, the parents in this study believe medical and other professionals need to appreciate parents’ instincts and give credence to their expertise and concerns.

Theme 3: reactions to the diagnosis

Because most boys are diagnosed with DMD in early childhood, it is the parents who are most devastated by the diagnosis. The earliest and most common reactions to the diagnosis included various stages of the grief process. The DMD Forum (2001) explains this process clearly and succinctly. One of the first reactions is denial.

No, I can’t accept this. How can a paediatrician make that diagnosis right there? I got on the phone with him that night and I said, ‘How can you be sure? I want a second opinion’.

Denial quickly turns to anger. The anger is intense because it is brought on by grief and inexplicable loss.

I was angry. I passed through denial but got stuck in anger for a long time.

I cried and cursed God. I was just so angry. I don’t think I’ve ever gotten over that anger.

Another response is fear. Parents fear the future. They often imagine the worst possible scenario.

I spent hours agonizing over all the possible bad things that could happen in my son’s future.

Guilt is a common response to grief as well.

I felt exacerbated guilt for my son’s disorder because an insensitive medical professional told me that it is passed on by the mother.

After guilt, parents may face confusion, powerlessness, disappointment or rejection. It is important for parents to know that the grief process is a universal response to overwhelming shock or grief. It is equally important for medical professionals to be aware of ‘the grief process’, and to handle the diagnosis with empathy and offer suggestions for working through the initial shock. This provides support to the parents until they develop the coping skills necessary to deal with DMD.

Theme 4: treatment

Although there is no treatment to halt the progression or cure DMD, willing and enlightened parents
have several treatment options available to help slow the progression. Some doctors advise parents to rely on normal activities such as swimming, horseback riding, and modified sports and games as long as possible. This can be proactive:

We encouraged our son to do as much as he was able, but we steered him toward low impact activities like swimming, bike riding, and karate.

or reactive:

The doctor’s theory was ‘Leave the kids alone. Let them live their lives as best they can, get them a good wheelchair when they need it’.

Daily stretching of the joints is a must to prevent contractures, which hinder movement. One mother describes their solution:

When my son was in first grade, he called muscular dystrophy ‘stretching disease’ because we instituted a stretching program at school. Everybody in the first grade stretched together every morning.

Doctors have begun to prescribe steroids to slow progression and keep boys walking longer. This treatment, proven to increase muscle mass, strength and pulmonary strength (Cwik & Brooke 1996; Porter et al. 2001), is controversial. Steroids may produce side effects such as weight gain, fluid retention, eye cataracts, diabetes, osteoporosis, and severe psychological conditions (Porter et al. 2001). Each family must weigh the risks and decide what is best for their son.

We never put our son on prednisone. We were more concerned about quality of life, and didn’t like the possible side-effects.

Our son is on deflazacort and doing well with it. He is still able to stand at age 13.

The most invasive treatment for DMD is preventive surgery. In younger boys, this includes ankle, knee, or hip tendon release. The tendons are surgically cut to prevent disabling contractures. In older boys who use a wheelchair for mobility, spinal fusion is performed to prevent scoliosis (curvature of the spine).

Theme 5: equipment

In addition to specific treatment options, parents and their sons rely on special equipment. Young boys with DMD are likely to use ankle-foot orthotics (AFO’s) and night splints, to prevent contractures of the ankles and feet.

AFOs make it easier for our son to do things, and also to prevent contractures. He has daytime AFOs at school which allow some bending and keep him active.

As boys with DMD get progressively weaker, they use equipment to keep them mobile. The parents of newly diagnosed boys may think of a wheelchair as the ‘beginning of the end’ and dread the time when one becomes necessary. However, parents find that progression is a gradual thing and when a wheelchair is needed, it becomes a tool to help boys with DMD maintain independence.

By the time our son needed to use one, it was such a relief.

The PT told me that a wheelchair is good for my son’s independence. So I try to see it as a tool that will help him.

Other essential equipment to maintain quality of life may include ramps, lifts, accessible showers, hospital beds, modified vans for transportation and accessible homes.

Theme 6: school issues

When boys start school, parents or teachers may notice other symptoms such as lack of phonemic awareness, difficulty with abstract reasoning, poor organization skills, and language difficulties. Veronica Hinton's studies indicate that boys with DMD often have communication and auditory processing difficulties (Hinton et al. 2000). At least
five of the boys in this study had speech and language delays. Parents suggest:

Use sign language, pictures and other visuals to help the boys understand what they need to do.

Processing difficulties are also common. Boys with DMD and processing disorders benefit from receiving small, concise pieces of information both orally and in writing. Parents and teachers find it helpful to check often for understanding, and provide necessary cues to ensure follow through.

Although short-term memory is also a weakness, visual memory and long-term memory are often very strong for boys with DMD. Parents believe that educators should use these strengths to develop effective interventions.

He has a great memory for maps and directions.

He loves space and is not interested in much else. His space vocabulary and factual knowledge are huge.

He can tell you a lot of real interesting facts about dinosaurs or plants or tropical rain forests.

Boys begin to feel the physical effects of DMD at about the time they begin school. Therefore, education is a very important issue to parents. The parents of the younger boys, especially, believe in early intervention for speech and language delays, occupational therapy, physical therapy, counseling, and socialization. Parents of the older boys are more concerned with developing appropriate IEP’s to meet their sons’ particular needs. All of the families highlighted the importance of home-school cooperation.

We can’t expect an educator to be well versed in many different disabilities. We have to educate them and work with them. The more we do that, the more willing teachers are to work with our children.

One family has home schooled all three of their children. For their son with DMD, home schooling has physically benefited him by enabling him to spend more time standing, and to have access to the necessary accommodations. Academically, he has benefited from one-on-one instruction, strategies tailored to meet his particular needs, and the opportunity to learn based on his interests. His mother asserts:

You are your son’s primary educator. Don’t shrink back and let other people take over in the area of education.

Parents in this study had definite ideas about what was needed to improve their children’s education.

Education has benefited from including kids with disabilities in general education classes. But there are times when kids also need one-on-one instruction.

His preschool established routines and did a lot of repetitive instruction to draw the children out.

Collaboratively, parents and teachers have developed effective strategies for boys at all stages of progression. In the present study, approximately 67% of the 18 boys also had learning difficulties in language arts and/or math.

He does not have phonemic awareness and does not understand phonics. I used a video based phonics program that incorporated hearing, listening, and writing that helped him with reading.

I use a home-school program for my son that enables him to use all the senses in learning to spell.

My wife cut the spelling words out of sand paper so our son could spell using both visual and kinesthetic learning modes. He needed to touch and see to make the connection.

Math is a little too abstract for him. He learns fine if he uses an abacus, a number line, or manipulative counters.

Parents also have the responsibility to see that schools provide the necessary accommodations so
that students receive an appropriate and accessible education.

His occupational therapist at school got him a different chair and a slant board to write on. Because it is hard for him to sit 'Indian style' on the floor, we sent two TV chairs that sit on the floor to school. One chair is for our son. His classmates take turns sitting in the other chair and being his playmate at recess.

Adaptations such as ramps and elevators are becoming more commonplace in schools. However, restroom modifications are a necessity often overlooked.

When he was in middle school, he was unable to use the facilities in the adapted restroom because he couldn’t get his wheelchair close enough to the toilet.

Some parents also rely on medication to help their sons at school. Because attention problems are sometimes an issue for boys with DMD, Ritalin and similar medications may help them focus and stay on task.

He uses time-release medication to help him focus.

My son is on a number of medications. To be honest with you, when we live with him off medication his life is unbelievable. He’s not happy. His quality of life isn’t good.

Discussion

This study provides several implications for professionals who work with children who have DMD. Medical, educational, and other professionals can learn and benefit from the lived experience of parents who cope with DMD on a daily basis.

The first issue that parents cope with is the diagnostic process. Most of the families in this study noticed atypical physical signs such as enlarged calf muscles, tip-toeing, the ‘Gower manoeuvre’, frequent falling, and fatigue when their sons began walking. Although parents did not want to believe that these symptoms indicated a serious condition, they were anxious to find an explanation. In some cases, the parents felt they had to convince the doctors to take them seriously and run diagnostic tests.

After the diagnostic process, parents begin a new life with a son who has DMD. Through their lived experience, parents in this study demonstrated their resiliency and ability to develop effective coping strategies. Although DMD progression varies from person to person, even those who are siblings or first cousins, participants reported that they were quick to adjust to and cope with increased weakness and dependency as the disease progressed.

Contrary to parents’ reactions noted in the literature, such as Buchanan et al. (1979) who found parents used the coping mechanisms magical thinking, overprotection, and lack of child discipline, and Holroyd and Guthrie (1986) who found that parents of children with neuromuscular disease are pessimistic about outcomes relating to the disease and have negative feelings toward the child, most of the parents in this study coped realistically and positively. They began by taking one day at a time, learning as much about the disorder as possible, talking to other parents, adjusting their priorities and slowly getting involved in new ventures. Parents appear to have become more proactive over time as indicated by their knowledge of the causes of the disorder, what to expect as the disease progresses, how to get appropriate support, and where to go for the latest information on results of research studies.

Although there is still no cure for DMD, families make use of various proven treatments to slow progression and improve quality of life. Stretching and low impact sports are recommended by doctors and encouraged by parents to keep the boys active and flexible. Orthotic devices such as plastic braces and splints are used to prevent muscle contractions. Tendon release surgery is used as a last resort to keep the boys on their feet as long as possible, and spinal fusion surgery is the only option available to treat scoliosis that develops when the boys use wheelchairs full-time. However, steroid therapy such as prednisone (Cwik & Brooke 1996) and deflazacort (Parent Project Muscular Dystrophy...
2000) is now available to maintain ambulation for an extra year or two.

There is more adaptive equipment to improve mobility and quality of life. In this study, parents report their sons successfully use canes, walkers, electric scooters and power wheelchairs to maintain their mobile independence. The parents use modifications such as lifts, bars, shower chairs, modified vans, and ramps as aids to assist in caring for their sons.

Along with the steroid treatment and modernized equipment, parents also have access to the Internet. The vast amounts of information available to parents has done much to ensure a more proactive and positive outlook. Parents indicated very clearly that they will do whatever is necessary to maintain normal lives for their children. Additionally, these parents are willing to readjust their attitudes to improve the quality of life for their sons with DMD and everyone else in the family.

Findings in this study reiterate the value of relying on parents as sources of expert and practical advice. These parents operate on the theory ‘knowledge is power.’ They have become knowledgeable experts on DMD and its ramifications and have established a sense of community through sharing of information to empower others like themselves. Perhaps, most importantly, they have set positive, but realistic goals for their sons.

Implications for professionals

Medical, educational and other professionals can learn and benefit from the lived experience of parents who cope with DMD on a daily basis. The following implications are suggested for professionals who work with children who have DMD:

1. Appreciate the parents’ instincts and give credence to their concerns.
2. Be aware of the grief process, handle the diagnosis with empathy especially concerning genetic inheritance and offer suggestions for working through the initial shock.
3. Work cooperatively and collaboratively with parents:
   • to obtain the necessary equipment as the disorder progresses;
   • to check often for understanding, and provide necessary interventions to ensure follow-through in learning;
   • to utilize multisensory approaches to instruction; and
   • to ensure universal accessibility for children with DMD.

Acknowledgements

This research would not have been possible were it not for the 23 parents and in one case, two adult sons with DMD, who voluntarily agreed to be interviewed. All of them contributed immeasurably to the findings and to my knowledge of how parents in particular and families in general cope with the lived experience of DMD.

References


Appendix A

Sample questions

1. First of all, I’d like to know more about your son.
2. Could you describe the early symptoms that made you wonder, ‘Is my child different physically, behaviourally, or in the way he learns?’
3. Describe your experiences before and after both diagnoses.
4. What were your reactions to each diagnosis? Mom? Dad? Siblings? Your son’s? Describe what that time was like for your family.
5. Describe the strategies you use to help (name of child):
   • with schoolwork,
   • accept his disabilities, and
   • overcome his disabilities.
6. What advice would you offer to parents in the same situation?

Appendix B

Open codes set one

Memory for facts
Age at diagnosis
Motor delays
Medical personnel
CPK
Reactions to diagnosis
Early childhood special education
Treatment options
Communication issues
Home and School cooperation
Home schooling
Interests
Mother-sibling diagnosis
DNA
Focus
Live day by day
Early symptoms
Life changes
Parents’ responsibilities
Support from others
Muscle biopsy
Family history
Inclusion
Discrimination
Wheelchairs
Normal life
Stretching disease
Accessibility
Modifications

Appendix C

Axial codes set one

Strength
Diagnosis
Delays
Medical personnel
Education
Support
Treatment
Descriptive traits
Coping
Quality of life
Interests
Physical challenges
Parent involvement