Gender-specific differences in the psychosocial adjustment of parents of a child with duchenne muscular dystrophy (DMD)

Two points of view for a shared experience

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ABSTRACT

Research was conducted on parents’ experience of caring for a child living with Duchenne muscular dystrophy (DMD). The focus of this research was on the key psychological aspects of the process of adjustment to the illness of their child (family and spousal relationship, daily life, emotions, career, spirituality, and coping strategies). There was evidence throughout the study of gender-specific differences in constructing the different aspects of the shared experience.

The main findings included major differences in the initial reaction and coping styles between mothers and fathers. These differences could be perceived as a threat or could serve as a source of isolation between parents. Additional findings included the unequal sharing of caregiving tasks between partners: the primary caregiving role usually being assumed by the mother, with the father playing a supportive role. The unique contribution of this study in further describing the lived experience of parents of a child with DMD is its attention to the internal dynamic of the relationship between mothers and fathers. This dynamic is highly dependent on the respective roles of primary and secondary caregiver.

This research has implications for the design and implementation of intervention strategies aimed at couples caring for a child with DMD, or with other severe, chronic, and uniformly fatal illnesses.

Keywords: gender differences, parental adaptation, childhood chronic illness, Duchenne muscular dystrophy (DMD), coping, psychosocial adaptation
INTRODUCTION

Our research team is chiefly composed of health care professionals involved in the care of children with chronic illness. Our medical specialties include Neurology, General and Metabolic Genetics, Occupational Therapy, and Social Work. Several members of our team provide primary care in our institution’s Neuromuscular Clinic and have extensive clinical experience in the care of children with Duchenne muscular dystrophy. As individuals, we are all keenly aware that not all answers to treating medical illness are provided by the natural sciences and hope that we may bring more to parents than just scientific knowledge and pharmacologic treatment. We hope that by pursuing qualitative research, which remains underrepresented in our institution, we may provide a link that is missing between the natural and social sciences, and add a scientific value that is provided by qualitative research. Our experience of the limitations of basic and clinical science in providing answers and comfort to parents of children living with Duchenne muscular dystrophy led us to approach a qualitative researcher with the aim of performing collaborative studies in parents of children affected by this illness. This qualitative researcher’s expertise in adaptation to chronic illness and life transitions in adulthood was instrumental in allowing us to perform this study.

BACKGROUND

Duchenne muscular dystrophy (DMD) is a genetically determined, progressive and incurable neuromuscular illness in boys, caused by mutations in the DMD gene located on the X chromosome. Lack of the protein dystrophin, encoded by the DMD gene, leads to progressive loss of motor function, beginning in early childhood, and to loss of ambulation resulting in wheelchair dependence, usually by the teenage years. The disease is uniformly fatal. Median survival for individuals affected by DMD is currently 17 years, with few individuals surviving beyond the third decade (Korf, Darras, & Urion, 2003). Many affected boys exhibit some degree of cognitive impairment (Gilberto, Ferreiro, Dalamon, & Szijan, 2004; Polakoff, Morton, Koch, & Rios, 1998), and the majority will develop cardiac complications after age 18 years. Respiratory complications are frequent, and contribute to early mortality.

Jacob (1989) has described four distinct clinical stages in the evolution of illness: Early Ambulation phase (ages 2 to 5 years); Late Ambulation phase (ages 6 to 9 years); Early Wheelchair phase (ages 10 to 13 years); and Late Wheelchair phase (ages 14 years and older). Each has characteristic challenges and unique needs to be addressed by the multidisciplinary health care team, including genetic counselling and testing, optimization of physical function, pharmacologic therapy, assessment of respiratory function, and discussion of assisted ventilation and palliation.

Although the challenges to be faced by a family with a child affected by DMD are, in part, those shared by families dealing with any chronic illness, there exist unique aspects of DMD that present a particular challenge. The clinical course of boys with DMD follows a well-defined pattern of loss of specific skills, progressive deterioration, and ultimately death. Losses are compressed into a short period of time, and the constant evolution of disability precludes periods of stability, where families feel confident with trusting the care of their child to outside caregivers. The nature of care provided is constantly changing. The expectation of the ultimate outcome, however, is uniform: the inevitable death of the child.

DMD has been described by Nereo, Fee and Hinton (2003) as a ‘complex chronic condition’ with effects on the family similar to both chronic and terminal illnesses.
They describe the following psychologic adjustments encountered by the family in this situation: facing separation and loss; experiencing and expressing emotions; and changing values, expectations, roles and responsibilities. The complexity of this psychologic adaptation, not surprisingly, results in considerable stress in families caring for a child living with DMD.

Psychologic stress in families with a child with DMD

Research to date indicates that the majority of families having a child with DMD experience significant chronic psychologic stress, and that the level of this stress is higher than that found in families with healthy children or with children affected by other chronic diseases (Holroyd & Guthrie, 1986, cited in Reid & Renwick, 2001). Thompson, Zeman, Fanurik and Sirotkin-Roses (1992) in a study of 35 children with DMD, found that 57 per cent of parents had self-reported poor psychologic adjustment. Abi Daoud, Dooley and Gordon (2004) reported that Canadian parents of children with DMD had a higher probability of having a major depressive episode than the population at large, based on a national survey on the health of the Canadian population. Nereo et al. (2003) examined stress in 112 mothers of children with DMD and compared this group to mothers of healthy children (n=800) and mothers of children with cerebral palsy (n=28). The authors confirmed that stress in mothers of children with DMD was greater than that experienced by mothers of healthy children, and related this elevated level of stress to child behaviour problems and stressful interactions between the mother and child. They hypothesize that decreased social awareness and competency in boys with DMD present particular difficulty for their caregivers.

Buchanan, LaBarbera, Boelofs and Olson (1979) studied 25 families with a child with DMD in the United States and found that 76 per cent of parents identified some psychologic aspect of the illness as their major problem in adjustment to this illness. The authors described the stress of living with a child with DMD as a chronic psychological stress, due to the strain of chronic illness, prolonged grieving, guilt and anticipation of impending death.

One of the largest studies to date of parents of boys with DMD was carried out by Firth, Gardner-Medwin, Hosking and Wilkinson (1983) in the United Kingdom. In their cohort of 53 families, multiple problems were identified by the parents, including practical and service-related problems, as well as emotional and communication difficulties. In a more recent study of 35 Canadian families with a child with DMD, service and practical issues were also identified as most important, but mental health issues, particularly social isolation, anger and depression were also ranked as very significant (Bothwell et al., 2002).

Qualitative research studies in families with a child diagnosed with DMD

Relatively few studies with a qualitative design have addressed the psychosocial aspects of DMD. Witte’s (1985) narrative description of UK families with an adolescent affected by DMD, stresses the isolation of these families from mainstream normal culture, as well as parental preoccupation with the illness, decreased expression of enjoyment, and difficulty in communication about death issues. Fitzpatrick and Barry’s (1990) cultural differences study examining parents of Irish and American boys with DMD also highlights the high frequency with which parents report difficulties in communicating with their sons about their illness. Within the Irish sample the authors were able to demonstrate a correlation between communication difficulties between the spouses and the presence of psychiatric disorder (mainly depression) in the affected boys.
Qualitative research addressing the adaptation of the family to this illness has also been undertaken by Bregmann (1979, cited in Gagliardi, 1991a) and Gagliardi (1991b). Bregmann identified five parental experiences: 1) Change in focus from future to present; 2) Efforts to normalize family life; 3) Attempts to minimize family vulnerability; 4) Development and capitalization on personal strength; and 5) Use of support networks. Gagliardi described six themes that characterize the experience of living with a child with DMD: 1) Erosion of hope for normalcy; 2) Society’s confirmation of the impossibility of normalcy; 3) The dynamics of the family; 4) A smaller world; and 5) Letting go or hanging on; and 6) Things must change (Gagliardi, 1991b).

Several coping mechanisms that have been used by families of a child with DMD have been described by researchers studying family adaptation. These include: denial, magical thinking, and over-protection (Buchanan et al., 1979). More recently, Webb (2005) has highlighted the importance of active coping in families with a child with DMD. By actively participating in their son’s lives, and by becoming experts in DMD parents were better able to cope with the stresses of the illness.

Buchanan (1979) attempted to characterize the best adjusted families and has identified four commonalities: 1) Open communication between spouses; 2) Orientation towards the present; 3) Organized, routine recreation for parents; and 4) Support from outside the nuclear family.

What emerges from the available literature to date is the considerable stress experienced by all individuals within the family unit of a family living with a child with DMD. The experience presents specific psychologic and adaptational difficulties in parents and in siblings of the affected child. What has not been extensively examined to date is how each individual parent experiences and adapts to living with a child with DMD, and the impact of the illness on career development in mothers and fathers.

The impact of gender on the experience of caregiving for a child with chronic illness

There now exists a considerable body of knowledge concerning gender differences and similarities in the experience of parenting a child with chronic illness. Research studies have demonstrated that significant differences exist between mothers and fathers in several domains, including adaptation, perception of severity of illness, social support needs, self-esteem, coping behaviours, marital satisfaction, and involvement in the care of the child (Katz, 2002). Most research studies have, however, been quantitative in design (Pelchat, Lefebvre, & Levert, 2007), and have been judged to show contradictory and inconclusive findings (Katz, 2002; KnafI & Zoeller, 2000).

Very few studies have compared parents within the same family and these studies have been restricted to families with a child suffering from hearing impairment, intellectual disability, diabetes, cancer, or a variety of chronic diseases that did not include progressive neuromuscular disease.

In a study of parents of a child with diabetes, Leonard, Kratz, Skay and Rhenberger (1997) reported more areas of similarity than of difference between mothers and fathers. Likewise, Knaffl and Zoeller (2000), using both quantitative and qualitative measures, found that mothers and fathers of a child with chronic illness were likely to hold a similar view of the major aspects of the illness and similar perceptions of family and individual functioning. Agreement was high in four of five qualitative themes examined (Child’s identity; Illness as foreground; Parental mutuality; Transformative experience), but less agreement was found in the Management mindset theme, with few fathers taking on the primary responsibility for illness management.
In contrast, Pelchat, Lefebvre and Perreault (2003) report more differences than similarities between the experiences of mothers and fathers raising a child with Down’s Syndrome. In simultaneous discussion groups of four couples and one mother, two main themes were identified: 1) Actual and expected roles; and 2) Normalization/stigmatization of the child. The authors demonstrated that fathers’ expectations of their role in the family were attuned to the exterior world, whereas mothers took on the primary caregiving role, even if both spouses worked outside the home. Fathers appeared to want their child to be thought of as normal, while mothers stressed their child’s individuality. Other important differences to emerge from this study were differences in perception of the situation, differences in coping, differences in relationships with the health care team, and differences in communication style.

A recent systematic review of the literature has permitted the characterization of an overall profile of the experience of fathers and mothers in parenting a child with a health problem (Pelchat et al., 2007). Both differences and similarities exist. Mothers are more likely to experience emotional distress than fathers. Fathers are more likely to experience couple-related distress. Mothers universally have more parental responsibilities than fathers and centre their lives around the child’s illness. Fathers have higher expectations of their child and experience more stress with stigmatization of the child’s illness. Fathers and mothers utilize different coping strategies and differ in their social support needs. Parents differ in their utilization of health care resources and in their interactions with health professionals. Based on their review of the available literature, the authors conclude that further qualitative studies are needed to address the gaps in current knowledge concerning the individual experience of mothers and fathers in caring for a child with chronic illness (Pelchat et al., 2007).

AIMS OF THE STUDY

Our research objective was to describe and contrast the lived experience of mothers and fathers of children with DMD. We set out to characterize this experience as viewed from the point of view of a primary caregiver versus secondary caregiver (support person for the primary caregiver). In order to achieve this goal, we made a decision to interview separately the mothers and fathers of a child with DMD.

METHODS

1 Choice of methodology

Methodology research models are deductive and quantitative or inductive and qualitative. The hypothetical-deductive paradigm is based on the premise that an independent, objective reality exists outside the individual (Smith, 1993). This reality can be observed, measured, and explained. Research aims to identify cause and effect, from which universal laws can be deduced (Guba & Lincoln, 1994). This approach is based on the development of a hypothesis aimed at explaining a particular phenomenon. The validity of the hypothesis is tested by measuring observable, quantifiable facts (Guba & Lincoln, 1994). Findings are always quantitative and can be generalized to all similar contexts and results can be reproduced by others under similar conditions (Guba & Lincoln, 1994; Smith, 1993). A key component of this paradigm is the researcher’s detachment and objectivity. Two difficulties arise with this approach. First of all, reality is ‘cut’ into segments, which are either proven or negated. Second, the researcher is limited to a precisely defined aspect of reality and cannot develop an integral view of a particular phenomenon.
The holistic-inductive paradigm is characterized by the recognition of the subjective nature of reality. Reality is viewed as a construct of the individual based on emotions, values, and culture (Samson, 2000). The objective of research is to understand the significance to the individual of a particular lived experience. This perspective is inductive, holistic, and naturalistic (Bachelor & Joshi, 1986). As the experience of the individual, as reported by the person, is the sole source information, the researcher is interested in the significance the subject ascribes to a particular experience. There is no hypothesis to be verified. Researchers attempt to understand a particular phenomenon from the perspective of the subject. The widest possible angle is opened on the experience by viewing it within the context of the participant's natural experience. Researchers empathize with the subject in order to understand the experience from the individual’s subjective perspective (Jacob, 1988). While generalizations cannot be made from this type of research, findings can be transferred to similar contexts (Guba & Lincoln, 1994).

As the intention of the present study is to describe the natural lived experiences of the participants in their own contexts, the use of the holistic-inductive paradigm is most appropriate. Among the methodologies of the holistic-inductive paradigm a phenomenological approach meets the objectives of the research. In qualitative research, the phenomenological tradition is rooted in the philosophical approach developed by Husserl (1950). For Husserl, the foundation of knowledge rests on the subjective experience. In other words, reality is not in the objective world, but in the way that it is perceived by the individual. In the phenomenological tradition, various data analysis methods have been developed (Giorgi, 1997). The Empirical Phenomenological Psychological (EPP) data analysis method proposed by Karlsson (1993) was used in this study. This method is divided into five stages, which were followed in the present research. The first in the process is to carefully read and reread each individual participant’s testimony in order to arrive at an empathetic understanding of the subject’s experience. In the second stage, each verbatim is separated into individual units of meaning. Each new topic raised in the verbatim is a new unit of meaning, always seen within the context of the entire testimony. During the third stage the units of meaning of each verbatim are interpreted and an initial abstraction of the meaning is made. In the fourth, each verbatim is interpreted to the highest level of abstraction possible in order to draw out the essential elements of the experience as perceived by the participant. Finally, in the fifth stage, the common elements of testimony are identified and the essential elements described. To enhance trustworthiness, the analysis was done by a team of three researchers (AS, SM, ET), using the consensual approach as described by Samson and Zerter (2003).

2 Entry criteria and subject recruitment

To be eligible for study parents were required to have a child with DMD, at any stage along the disease trajectory and needed to be able to communicate in either English or in French. Participants were given a choice as to which language they would use to complete the interview. In the initial phase of the study we limited enrolment to parents of boys in the Early and Late Wheelchair phase. Their experience forms the basis of this report.

Study participants were recruited at the Neuromuscular Clinic of the Children’s Hospital of Eastern Ontario (CHEO). Mothers and fathers of children with DMD were first approached by one of the members of the clinical team having regular contact with the child with DMD. Signed informed consent was obtained prior to the completion of a demographic questionnaire and prior to the interview.
3 Interviews

We conducted semi-structured interviews with 11 parents of children with DMD. Mothers and fathers were interviewed separately by one of the principal investigators (AS, ET). For five couples, both the mother and the father were interviewed. For the last couple, only the mother consented to be interviewed. Interviews were conducted in either the English or French language. Interviews were taped and later transcribed. The average length of the interviews was 90 minutes.

Each participant was asked to describe his or her experience of living with a child with DMD, using a written Question Guide (see Appendix). In all of the interviews, only three types of interjections were to be made by the interviewer. First, if the participant stopped talking for a prolonged period of time, he or she was asked to re-read the question. Second, if the participant’s comments seemed to be unclear, he or she was invited to clarify them. Third, if the participant spoke too quickly, he or she was asked to stop so that his or her testimony could be transcribed accurately.

RESULTS

Demographics

Demographic details of the families studied are presented in Table 1. Five of the six children affected with DMD were boys, while one was a girl. The median current age of the child was 12.5 years (range 10 to 14). Median age at diagnosis of DMD was 4.5 years (range 3 to 8 years).

Median age of the mothers was 40.5 years (range 40 to 49). Median age for the fathers was 47 years (range 44 to 58). At the time of diagnosis of DMD in the child, the median age of mothers was 32.5 years (range 31 to 41). Median age of fathers at the time of diagnosis was 40 years (range 34 to 52). On average, eight years (range 7 to 10) had elapsed since time of diagnosis to date of interview.

All families had only one child affected by DMD. In two families, the child with DMD had been adopted by the parents. In the remaining four families, the parents were biological parents of the child with DMD. All children with DMD had siblings, sometimes adoptive. The age range of the siblings was 6 to 26 years.

In four families there was no family history of DMD. One adopted boy had a biological uncle with DMD. In another family, there was a history of DMD in two fifth-degree relatives. Two of the mothers were known to be carriers of DMD. Two had been tested but were determined not to be carriers of DMD. In the remaining two families the mother was not the biological mother of the child with DMD.

In four families, caregiving was seen by both spouses to be equally shared by the spouses, although there may have been a stated division of caregiving tasks (for example, split between being primary caregiver for physical needs of the child and primary provider of emotional support). Two mothers clearly identified themselves as the primary caregiver for the child with DMD, although in one of these families the father perceived caregiving to be equally shared by the spouses.

Nine of the 11 parents had completed a college (6 parents) or university (3 parents) education. Two mothers had completed or partially completed high school. Three of the six mothers were working outside the home (2 at part-time hours and 1 at full-time hours) at the time of the interview. Of the three mothers who were not working outside the home, two had held paying jobs prior to the need to stay home to take care of the child with DMD. One mother had previously participated in the running of the family
farm but with the increasing demands of caregiving for the child, hired help had taken on her previously held responsibilities.

From a demographic point of view, one couple was very different from the others: the father was retired and stayed at home during the day with his affected child. His wife was the only mother in our study who was working outside the home on a full-time basis. This couple had adopted five children, including one girl with DMD. This child with DMD was adopted at a time when the father was close to retirement age but the mother was still developing her career. In this family, caregiving was provided by the stay-at-home parent. This family’s experience contrasts with all other families where both spouses were at earlier stages of career life.

The six mothers and four of the five fathers each considered themselves to be a spiritual person. All six mothers and three of five fathers identified themselves with a particular religion. Four mothers and one father sought support from their religious community.

With the exception of one couple and one additional father, all participants considered that the financial demands of DMD had an impact on their ability to cope.

**Table 1: Demographic details relating to the families studied**

<table>
<thead>
<tr>
<th>Demographic variable</th>
<th>Mothers</th>
<th>Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current age</td>
<td>40–49 (median 40.5)</td>
<td>44–58 (median 47)</td>
</tr>
<tr>
<td>Age at child’s diagnosis</td>
<td>31–41 (median 32.5)</td>
<td>34–52 (median 40)</td>
</tr>
<tr>
<td>Identified themselves as primary caregiver</td>
<td>2/6</td>
<td>0/6</td>
</tr>
<tr>
<td>Viewed caregiving as equally shared</td>
<td>3/6</td>
<td>4/5</td>
</tr>
<tr>
<td>College or university education</td>
<td>4/6</td>
<td>5/5</td>
</tr>
<tr>
<td>Working outside home</td>
<td>3/6</td>
<td>4/5</td>
</tr>
<tr>
<td>Carrier of DMD genetic change</td>
<td>2/6</td>
<td>n/a</td>
</tr>
</tbody>
</table>

**Themes identified**

Analysis of the interviews identified five major themes within the experience of caring for a child with DMD in which important gender differences emerged: 1) Care of the Child; 2) Coping styles; 3) Partner relationship; 4) Career; and 5) Social support. These are described below with a few chosen quotations.

1 **Care of the child**

A mother’s story

Being the primary caregiver is perceived by the mother to be a full-time occupation. There are multiple physical demands, and little outside help. Daily life revolves around the needs of the ill child: the practical needs to be bathed, dressed and fed. Additional demands are placed on the primary caregiver to find the resources for special equipment needs (wheelchair, van) to permit ambulation/transportation to school and family activities.

Being the primary caregiver allows the mother to develop a special relationship with the child. She recognizes the importance of her role, especially in providing tenderness and a place of security for the child. In providing constant care, a special bond is created between mother and child, and the mother becomes acutely aware of her child’s suffering...
and limitations. Occasionally this close relationship can lead to frustration within the couple relationship, particularly if the father feels excluded or incompetent in providing certain aspects of care.

The supporting parent is sometimes seen as being absent from the experience of caring for the child, and there is a sense that the stay-at-home parent bears the heavier burden. When the caretaking responsibilities continue for many years, there may be resentment for a life not fully lived, and opportunities lost. As the illness progresses and the child becomes more and more dependent, and as the outside contacts become fewer, the primary caregiver may feel more and more that he or she must provide the child with a sense of fulfillment. Coping is accomplished by focusing on day-to-day life.

‘A lot revolves around K. I have to be there in the morning. I have to help her get dressed. I have to feed her breakfast. I have to help her after the shower … Our whole daily life, our whole schedule revolves around K … It’s the fight for the services, the fight to get a lift for your van, to find money, to do this and that … everything is harder … It’s different. Your whole daily life. It’s a lot more work.’

‘Because all of a sudden there isn’t those people, there isn’t the sports, there isn’t that entertainment … she’s got no life. And then you become a life … You have to fulfil every moment of her day and make her a life because there’s nobody else there to make it for her …’

‘We were so immersed and we gave up so much over the years …’

‘Because I see it … there are times when he feels alone.’

‘I’m more gentle with him, pay more attention to his needs.’

‘J prefers that Mama takes care of him at certain times, because Papa is less patient.’

A father’s story
The supporting parent also has multiple needs to balance. The focus is on optimizing the time together; doing ‘normal’ family activities while the child is still capable, and enjoying a ‘normal’ parent–child relationship. Always close to the surface is the reality that the child’s life expectancy is short, and that further deterioration is inevitable.

Very often it is the father who is responsible for the physical adjustments that must be made in the home, and this contribution to the care of the child may bring considerable satisfaction. Although the father may be less implicated in the day-to-day care of the child, he also has his responsibilities: very often his unique contributions are in the moral and psychological domains.

Sometimes the father, or supporter of the primary caregiver, may feel left out emotionally and physically, especially if the child shows a preference for the other parent, for example, for comforting. Because the father is often not as intimately involved in the day-to-day care of the child, he may see himself as a helper to the mother, rather than taking on a primary caregiving role. Overall, however, there is an impression that the mother and father’s roles complement each other.

Some fathers find that by being involved in the day-to-day physical care of the child, their experience of the illness is enriched. They may become more aware of certain aspects of the personality of their son and are able to form a closer bond emotionally. This close contact facilitates the realization for each parent of the integral role that each has in accompanying the child through all the stages of the illness, including preparing for death.
‘I had the chance to spend time with him, to tease him, to put him to bed. Then he began to laugh at me, he found me funny … It was after that that I realized that something had changed. I don’t know exactly what … My attitude, yes. My attitude changed, but how did it happen, I can’t explain.’

‘We understood that we are important in the life of J. It is important to be with him.’

‘We reached a state of equilibrium, because with time we realized that we balanced each other.’

2 Coping styles

A mother’s story

For many couples, there is an entirely different initial reaction to the diagnosis of their child’s illness, and subsequently spouses often exhibit different coping styles. For the woman, talking and seeking the support of friends and family members is often identified as a primary way of coping, and the existence of adequate social supports is identified as more of a priority.

For the mother, coping entails finding the right time frame on which to focus. Looking too far into the future is difficult emotionally. Reflection on the past often serves to emphasize the child’s regression. Many mothers cope by concentrating on day-to-day life, although it is necessary to plan somewhat ahead, anticipating the next steps in the evolution of the illness and their associated physical needs. The present time is viewed as precious, an opportunity to bring happiness to the child, and to enjoy the time together.

‘Husband and wife deal very differently. I find that I had a lot of support from friends and family and wanted to talk about it as my husband was um, became more withdrawn and kind of internalized things and didn’t want to talk about it.’

‘He had his own way of dealing with everything that was going on … and I think we’ve developed a lot helping each other, talking … and I think we’re at a comfortable level as well where we’re happy.’

‘For me, it’s day by day. I take things as they come … I try not to think too far ahead, because then I get emotional.’

‘What happens is that you look too far down the road initially because you’re just learning and you want to be prepared … But then what I found out was I didn’t need to be 10 years down the road … So, I tried to find a place in the middle where I wouldn’t be 10 years down the road worrying about what was going to happen.’

A father’s story

For the male partner, seeking information, reflection and introspection, and planning and physically becoming involved in the provision of adequate physical supports for the child (such as wheelchair, van, home adaptation) may all provide means of cognitively and emotionally coping with the illness.

There seem to be some coping modes that are more associated with the primary caregiver than with the support partner. For the mother, these are the coping styles that allow her to take care of the child on a day-to-day basis. For the father, the important coping skills are the ones that allow him to oversee the overall functioning of the family unit. These may include skills that provide an optimal family environment.
‘Me, I don’t talk a lot. I keep it inside, usually … Her, she needs to talk to me … It helps her to understand.’

‘There’s a spiritual search that has to be done … Me, I was working more on that side. Her, she looked more on the social side.’

3 Partner relationship

A mother’s story

The woman recognizes the importance of effective communication between the spouses in dealing with the child’s illness. She is more likely to verbalize perceived differences in the coping styles of the spouses and to voice the difficulty the partners have in discussing openly the child’s illness, particularly in the earlier stages. Very often, the focus of conversation between partners is mainly on the practical aspects of the illness. The emotional, psychological, and spiritual aspects are rarely discussed. For some couples, the illness becomes ‘a box on the shelf’ that only comes out at times of medical visits or crisis. Although the woman may be sensitive to her partner’s difficulties in coping with the diagnosis or later events in the illness, she may not always explicitly voice this recognition, and an opportunity to provide support may be lost.

The woman recognizes her own need for an extensive support system, the need for family and friends with whom she can openly share her worries and emotions. She recognises her partner’s needs for reflection and introspection.

The different reactions of the spouses to the initial diagnosis or subsequent events can be misinterpreted and lead to misunderstanding between them. For example, the initial diagnosis is often a very emotional time for the woman, whereas her partner is less likely to express emotion. The mother may perceive her emotional behaviour as inappropriate or as a sign of weakness, when compared to the apparent strength of her partner. The mother may then feel that she is not understood in what she is going through. A difference in reaction, when misunderstood, can break the dialogue between partners. How the couple views their differences in coping styles is an important determinant of how well the partners function as a couple. Sometimes these differences are lived as a misunderstanding, especially where there does not exist open communication between the partners about the emotional aspects of the illness. Sometimes the differences are seen as a positive aspect, as providing a balance to the life of the couple and family. Learning to ‘live the differences’ may involve years of work, but seems to be associated with a deeper satisfaction of family life and couple relationship.

In the longer term, both partners appreciate the need to work together and to support each other in the experience of the child’s illness. It is this mutual support that characterizes those couples who grow as a result of this particular experience and who are able to integrate their child’s illness into a happy family life. The differences in coping styles in the two spouses may in the initial phases of illness serve as a source of isolation. In the longer term, differences are more likely to be judged complementary and as a source of balance.

The quality of the couple relationship is recognized to have a direct impact on the happiness and coping of the ill child.

‘I had the impression that he didn’t understand me, because he wasn’t expressing it the same way. He seemed to be much stronger than me, when it comes to emotion.’

‘We weren’t good supporters for one another because it was hurtful for us to talk together about it so we kind of separated on it for a bit and were still there to look after the needs of everybody else and ourselves, but it wasn’t something we talked about together.’
‘It wasn’t something that we openly talked about. It was put in the box on a shelf and we dealt with it when we had to come to CHEO.’

‘I think that J feels OK because he sees we are doing OK.’

A father’s story
The male partner may not necessarily feel the need to discuss the child’s illness, either with those closest to him or with other parents living the same experience. He may look at the situation as an opportunity to help his partner, and as a problem that needs to be fixed, rather than as a new reality that needs to be faced and integrated into the life of the couple and family. He may feel that the extra demands of the child’s illness detract from the quality of the marital relationship, and may reflect on and question the relationship itself. On the other hand, he may look at the shared experience of raising a child with DMD as enriching the quality of the marital relationship.

Although it may not be his style to want to discuss the illness, particularly its emotional and psychological aspects, the male partner recognizes the difficulty that the lack of communication brings: he may sometimes feel that he is having to guess at what his partner is feeling/experiencing; he may feel isolated from the experience of looking after the child. If the two partners learn how to empathize with each other, the differences in coping styles remain, but are seen more as tools to find equilibrium rather than a source of frustration.

‘Just too busy with family life to be a couple.’

‘I don’t feel the burning need to talk to somebody about this.’

‘We talk about what needs to be done, we don’t talk about what each other needs.’

‘It’s more guesswork now, trying to guess what the other one …’

‘We always had problems … but we learned with time how to communicate … It took time … Today it is going well. I would say that now, the illness brings us together.’

‘It has enriched our relationship. I see my spouse through the others, through the children. I see her interacting with the children. I see that she has changed over the years. She has adapted. I too have adapted. So we’ve reached an equilibrium.’

4 Career
A mother’s story
Although the stay-at-home parent recognizes the benefits of work outside the home (providing identity, balance, and a sense of wellbeing), the reality of a family with a child with DMD is that there is a need for at least one of the parents to provide the daily care for the child. This is a full-time occupation and often requires that a lifestyle change be made by the partner who will be the primary caregiver. Usually this becomes the responsibility of the mother, which means that she has no time or energy to invest in a paid job outside the home. The female partner feels limited by the boundaries imposed by the illness. She lacks personal space in which to develop as a person, until she realizes that the illness of the child itself could become a source of fulfilment.

Full-time employment is too stressful to contemplate and even part-time work is difficult because of the need for qualified outside help and support services. Very often, life is ‘put on hold’ by the stay-at-home parent. There is a sense that there is not enough appreciation and respect for the work provided by the primary caregiver of a child with chronic illness. There is a sense of isolation from others and lack of the necessary support.
‘I am a mother on a 24 hour basis … that’s my work.’

‘I think that once the diagnosis came, then you kind of put everything on hold for a long period of time.’

‘There still seems to be a lack of respect for the title of mother.’

A father’s story
Having an outside career can serve as an escape from the difficult reality of providing daily care to a child with DMD. Although adjustments are often required, for the most part the supporting parent is able to carry on with his (her) prior career, particularly if the workplace is supportive and if the individual is assertive in defining his (her) limits. For many, the experience of having a child with DMD is the impetus for a rethinking of life priorities, and often the prior importance given to career is overshadowed by the desire to have more time for family life.

For the parent who continues working, it is difficult not to bring the worries from home into the work situation. The added responsibilities intrude and can result in a loss of focus at work. Many fathers complain of fatigue, lack of interest, and problems with attention in the workplace. Despite this, the majority see themselves at an advantage as compared with their partner who has to stay at home.

‘Only time I can switch off now is when I drive 600 miles away.’

‘She, she has to stay at home … She is full-time here … whereas, I get to escape.’

‘The care of J is difficult. One doesn’t take it into consideration, but his care puts an extra weight on my shoulders.’

‘The career is not a priority for me. I have to think about many other things apart from career.’

5 Social support
A mother’s story
There exist fundamental differences in how spouses value and perceive the function of social support during their experience of living with a child affected by DMD. For the mother who, by the very nature of her home-centred role, is not part of the mainstream culture, social support is viewed as a way to get back into the mainstream. As such, social support is valued highly and actively sought. The mother is more likely to describe the importance of support provided by her family, friends, and health care providers. She is more likely to seek out and regularly attend a support group for parents of children with DMD. Overall, integration into society is a more difficult experience for the mother who is a primary caregiver for a child with DMD. Even though the mother of a child with DMD recognizes that major differences may exist between different families’ circumstances and their ways of coping, she views as very worthwhile the opportunity to share the common experience of having a child with DMD.

‘I think it’s good for families to be in touch with one another. I know some are open to that and some aren’t, but I really do think it’s a great support group because you’re going through the same thing and nobody else understands unless you’re having to do it, right?’

‘When I think about the people who impact my life and give me the most pleasure and enjoyment, and are the most helpful to me, they are the physiotherapist, who became a...’
close friend, the massage therapist and I who are like best buddies … the hairdresser who comes to my house … the babysitters that we’ve had who come by in the summer and take her out for no reason … my girlfriends who will come by and just drop in, and say Hi.’

‘If I could change something, I think I would ask for more people for more help along the way. And, uh, how do you ask for that?’

‘I was lucky to have a very big support system … It’s not the same any more even though it’s still there. Some people don’t even have (one) and I think that’s huge.’

A father’s story
For the father, social support is not as highly valued or sought. As an actively employed individual, the father considers himself to be part of the mainstream culture. The workplace provides him with self-image and a sense of fulfilment. He already feels integrated into society as a whole, and often does not see a need to seek out other individuals raising a child with DMD. He is less likely to attend a support group for caregivers and sees the differences that exist between families as an obstacle to any mutual gain in understanding. Because of his full-time work, the father may not have the same opportunity to attend support group meetings.

‘There’s got to be parents going through the same, but I see them with their kids and I can’t really relate to them because they seem to be all handling it in different ways.’

‘No, it was a bunch of women, it was all women. I was the only man.’

DISCUSSION
Our study highlights the tremendous burden placed on parents living with a child diagnosed with DMD. The care of the child is often perceived as an overwhelming, all-encompassing experience for the parents, who are frequently left with little outside support and inadequate social support. It confirms the previous findings (Abi Daoud et al., 2004; Buchanan et al., 1979; Nereo et al., 2003; Reid & Renwick, 2001; Thompson et al., 1992) of significant chronic psychologic stress in families with a child with DMD.

The unique contribution of our study in further describing the lived experience of parents of a child with DMD is its attention to the internal dynamic of the relationship between mothers and fathers. We describe that this dynamic is highly dependent on the respective roles of primary and secondary caregiver: the primary caregiver role is usually assumed by the mother with the father usually providing a supportive role. Our study shows that caregiving tasks are not equally shared between partners, but are divided, primarily on the basis of role. In the context of chronic illness, traditional stereotypes appear to be regenerated, with the mother providing daily care and the major emotional support for the child and family. The father’s major contributions are in overseeing the overall functioning of the family unit and in the moral and psychologic domains.

In our study, the importance of role over gender was exemplified in the unique experience of the one stay-at-home father. This individual’s experience had many parallels to the experiences of most mothers. His daily life was centred around his daughter’s special needs, the need for one parent to be at home for the child. Like most mothers, this individual experienced some degree of social isolation, a sense of carrying the heavier burden, and fatigue limited his ability to pursue interests outside the home. This father saw his own personal growth as being primarily in the emotional sphere, but placed more value on the career growth experienced by his spouse. The one area where
this father’s experience appeared to more closely resemble that of working fathers was in
his experience of couple-related distress.

Similar differences in mothers’ and fathers’ experiences in caring for a child with a
disability have been described in the work by Pelchat et al. (2003) in parents of children
with Down’s Syndrome. As in our study, division of roles was traditional in most couples
and the division of labor perceived as inequitable by some mothers. One of the important
conclusions drawn by Pelchat et al. (2003) was that there appeared to be no fundamental
difference with respect to roles and expected roles of fathers and mothers between
families with children with disabilities and those families with children who were not
disabled. The more recent systematic review by Pelchat et al. (2007) identifies two other
qualitative studies where differences in the experiences of mothers and fathers reflected
traditional gender roles. In Brown and Barbarin’s (1996) study of mothers and fathers
of a child with cancer, differences in the experience corresponded to traditional gender
roles. In Gray’s (2003) study of mothers and fathers of a child with autism or Asperger’s
syndrome, parental roles also reflected traditional norms.

Our study highlights the differences in coping styles between mothers and fathers of
a child with chronic illness. These differences at first may be perceived as a threat to the
relationship, or may serve as a source of isolation between the partners. With time,
couples learn to live the differences and in doing so, learn that the differences may be
complementary and enrich the life of the family. The process of living the differences is
difficult, particularly at the beginning of the experience, and can be seen as a lack of
dialogue. Dialogue appears to be the key necessary to find the desired equilibrium when
gender differences exist.

Our study suggests that professional help may be needed to help the couple to learn
to recognize and adapt to their differences. Parents recognize that their child’s perceptions
of the quality of the parental relationship profoundly affect their own adaptation to the
chronic illness in the family.

The experiences of the couples studied also suggest that, despite our current
multidisciplinary team management approach, the current medical model may not
optimally address the support required by parents of a child living with DMD, or with
other chronic illnesses. Such support optimally would include couple-based counselling
that focuses on communication and the quality of the couple relationship, and the
impact that these have on the wellbeing of the child. Such counselling may also include
discussion of the adaptive tasks faced by individuals in dealing with the chronic illness
of a child, and discussion of the different styles of coping. Support may also include
more general counselling in communication skills within the family unit. Although not
discussed in the themes elaborated above, the testimonies of our study participants
indicate that there exist particular challenges in parents’ communication with the
siblings of the child, especially about the illness and possibility of death. Siblings require
special support in coming to terms with their sib’s illness and their own reaction to the
altered family dynamics that arise as a result of the illness.

Optimal support for the couple and for the family unit would also include practical
help for the parents caring for their child at home: adequate skilled caregiver relief on a
regular and planned basis, to enable the primary caregiver to have adequate opportunity
to meet with her (his) much-needed social network, and to provide the couple with time
alone to nurture their relationship.

The finding that the vast majority of participants identified themselves as being
spiritual, and the fact that most had not had a previous opportunity to discuss their
spirituality in the context of their child’s illness, suggests the possibility of further
exploration of the use of spirituality as a coping mechanism in this context. Further
interviews are planned to better delineate the assignment of meaning to the illness by parents throughout the experience of caring for a child with DMD. These studies may suggest further intervention strategies that may help parents cope better with the demands of the illness.

There exist several major limitations to our study. First, with the exception of one couple where the father was retired and stayed at home to look after the child with DMD while the mother worked, the majority of mothers held the traditional role of mother, staying home to look after the child. Different experiences may have been recorded if families had had a less traditional structure. Second, our study included two families where the child with DMD had been adopted into the family, which probably over-represents the frequency with which this particular situation occurs. Last, the parents we interviewed had, on average, eight years experience in caring for a child with DMD. Different experiences may have been recorded by parents who had experienced only the early stages of evolution of the illness, or by parents who had completed the entire illness trajectory and whose children had died. We plan to further study such families and to compare their experiences with those of the families described in this article.

CONCLUSIONS

In conclusion, our study of the lived experience of mothers and fathers of a child with DMD contributes to the understanding of how families experience a chronic, genetically determined, incurable, neuromuscular illness. We had not expected that the major findings to emerge from our study would be the gender differences that exist in the experience, nor that these gender differences would follow traditional stereotypes. We were able to achieve our goal of better understanding the initial reactions and subsequent adaptation of parents by using an inductive approach, and by choosing to interview the members of each couple separately. Our findings support previously published reports of family adaptation to chronic pediatric illness, but bring a new perspective from the internal dynamic between mothers and fathers, and the study of DMD with its unique disease trajectory.

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REFERENCES


APPENDIX

Interview question guide—English version

I would like to ask you some questions. Please note that there are no right or wrong answers. Take as much time as you need, and answer as spontaneously as you can.

1. When you were first given the diagnosis of DMD for your child, what was your first reaction? (In the first few days? In the first month?) You may wish to talk about your feelings, your relationships, the way you saw your child and the future.

2. How did you make sense of what was happening at the time of diagnosis? In other words, did you see a purpose in that experience?

3. As a couple, how did it affect you? Did you discuss your child’s illness openly? How did you support each other?

4. How did the progression of the illness impact you?
   a. emotionally?
   b. your daily life?
   c. your relationships (with your spouse, other children)?

5. a. What does ‘spirituality’ mean to you?
   b. How did your spirituality play a role in your experience as a parent of a child with DMD?

6. On reflecting back on your entire experience, what would you say about:
   a. your family life?
   b. your daily life?
   c. the relationship with your spouse?
   d. your personal growth?
   e. the purpose of your existence?

7. Throughout your experience, could you please describe how your child’s illness impacted on your career. By career, we mean all the different life roles that you are currently carrying out, or have carried out in the past, whether or not you were paid for them. These life roles could include, for example: a paid job, your role as parent, citizen, or volunteer.

8. How did your child’s illness influence your life priorities when it comes to work/career?

9. Is this the first time that you have had the space to talk about that aspect (meaning/spirituality) of your experience?

10. Do you wish that you could have more space to talk about it (meaning/spirituality)?

11. On reflecting back on your entire experience, do you see a purpose in your child’s illness? In other words, how did it impact you as a human being in terms of:
    a. the way you see others?
    b. the way you see your family?
    c. your own spiritual growth?
    d. the way you see life in general?

12. Do you have anything else that you would like to add that we did not cover?
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