



# Listening to Fathers of Sons with Duchenne Muscular Dystrophy

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*Duchenne Muscular Dystrophy (DMD) affects the entire family, however, most studies concern maternal adjustment with fathers' adjustment largely overlooked. To investigate experiences of fathers of sons with Duchenne Muscular Dystrophy (DMD) interviews were held with 15 fathers of a son with DMD, from across the UK. 55 fathers from an associated study also provided written accounts. Grounded theory methodology was used to evaluate the data. Four key themes emerged: 1) loss and acceptance; 2) support versus isolation; 3) fight for resources and 4) race against time. Fathers de-*

*scribed the impact of emotional/behavioural factors, which were not routinely addressed by professionals. Findings emphasise importance of person-centred care, indicating how needs could be met, from fathers' perspectives.*

**Keywords:** Duchenne Muscular Dystrophy; experiences of fathers; qualitative research

Following ongoing campaigns by families and professionals, muscular dystrophy services have been the focus of ongoing developments at UK Government level. The All Party Group on Muscular Dystrophy (APGMD) was introduced in 2008, to raise the profile of the condition. However, it is evident from parent-led efforts (e.g. Action Duchenne), that families believe DMD is overlooked in Government health-care policy and service delivery. This neglect extends to the research literature where few studies have addressed the psychological consequences for parents who are caring for a child with DMD (Puxley & Buchanan, 2009), with most studies focusing on mothers.

Authors have suggested that studies based on coping of parents of disabled children, add valuable information to the research base (e.g. Webb, 2005). This is relevant in the context of DMD, where stress is heightened due to the high dependence of the child, associated learning difficulties, and continual deterioration (Nereo, Fee & Hinton, 2003).

### Duchenne Muscular Dystrophy

The muscular dystrophies are genetic conditions that are inherited or may arise without prior symptoms (Muscular Dystrophy Campaign). They have been described as 'chronic diseases manifesting with progressive muscle weakness' (Grootenhuis et al, 2007). Duchenne muscular dystrophy (DMD) is the most severe form, usually diagnosed between 2-5 years. More than 30,000 people within the UK have muscular dystrophy or related conditions and 120,000 individuals are indirectly affected as relatives/carers (Muscular Dystrophy Campaign).

Males are affected via transmission by an altered gene on the x chromosome, in a sex linked (recessive) inheritance pattern, with approximately 50% likelihood of a carrier's son being born with DMD (Dubowitz, 1982). The overall impact is a defect in dystrophin, the protein required for healthy growth of muscle fibres, resulting in severe disability, deterioration over time, and terminal prognosis. In addition to physical problems, DMD is associated with behavioural characteristics, with studies identifying high levels of behaviour problems, including limited social skills, attention deficits and depression (Leibowitz & Dubowitz, 1981; Thompson et al; 1992 Nereo et al, 2003).

Although ongoing medical developments are encouraging (Griffin & Des Rosier, 2009), research is at an exploratory stage, there remains no cure and boys have an average life span of 25 years.

### Understanding Parental Adjustment

Parents of boys with DMD report higher levels of psychological distress than controls (Thompson, 1992; Chen et al, 2002 & 2007; Holyroyd & Guthrie, 1986; Abi Doud et al, 2004). Notably, the child's behavioural problems, not the condition itself in terms of severity and care demands, leads to a detri-

mental impact on child adjustment (Nereo et al, 2003; Reid & Renwick, 2001). Parental adjustment is affected by witnessing indicators of deterioration in the child, social isolation (Firth et al, 1983) and negative parental attitude towards the child (Bothwell, 2002). A tendency to adopt unhelpful coping strategies such as withdrawal, isolation and overprotection, have also been reported (Gagliardi, 1991; Kornfeld & Siegal, 1979; Witte, 1985).

Where reported separately to mothers, fathers are found to display more difficulties coping with diagnosis (Firth et al, 1983) and may avoid contact with the child (Gagliardi, 1991). Unmet needs included support with child's communication and behaviour problems (Darke et al, 2006; Chen, 2008), and emotional problems (Firth et al, 1983). However, little information is available to describe the processes involved and fathers' perspectives.

### Significance of Paternal Involvement

Findings that child coping behaviour is promoted when family members are proactive in caring roles, (e.g. Lamb, 2004; Thompson et al, 1992) attests to the importance of paternal involvement in their care. Wysocki and Gavin (2006) suggest that paternal involvement may provide a 'coping resource that supports both mothers' and childrens' adaptive capacity'.

Evidence from both cross-sectional and longitudinal research indicates that paternal, more than maternal, involvement, protects against psychological distress in adolescents and young adults (Bogels & Phares, 2008) and improves quality of life in chronically ill adolescents (Wysocki & Gavin, 2006). The authors suggest that both quality and quantity of involvement have a direct impact on areas such as treatment adherence and frequency of reinforcement for condition self-management (Gavin & Wysocki, 2004; Wysocki & Gavin, 2006).

### Summary

Researchers have questioned the lack of psychosocial investigation into DMD, given the practical and psychological consequences on families (Puxley & Buchanan, 2009). Investigation of fathers in paediatric psychology literature is neglected (Phares et al, 2005), with available studies addressing maternal adjustment. Addressing calls for both, research within the area of DMD and inclusion of fathers, the aim of the study was to explore fathers' perspectives on caring for a son with DMD.

### Method

#### Participants

Fifteen fathers aged 34-60 (mean 48.4) of a son aged 8-32 (mean 16.1) with DMD, were recruited from across the UK. There was no restriction on the age of the child as exploration of a range of experiences was sought. Interviewees represented a broad range of experiences, covering early childhood prior to deterioration, adolescence, early adulthood and losing a son. The cohort of interviewees included a father as the sole carer, a father who had lost a child to DMD and a father of two boys with DMD. Fifty five fathers (from a related mixed methods study) also completed written 'comments sheets', comprising a summarised version of the interview guide. This technique allowed fathers to

respond to sensitive issues at their own pace, with the rationale that it might be easier for some to write about their experiences (Handy & Ross, 2005).

**Table 1.** Summary of Interviewees

Inter- view No	Region	Domestic situation	Age of fa- ther	Son's age at diagnosis	Age of Son	Years since diagnosis	Mode of in- terview
1	Scotland	With part- ner	46	2	12	10	Face to face
2	Scotland	With part- ner	60	10	25	15	Face to face
3	Scotland	With part- ner	57	In utero	21	20	Face to face
4	Scotland	With part- ner	51	3	13	10	Face to face
5	Scotland	With part- ner	46	At birth	15	15	Face to face
6	England	With part- ner	51	6	8	2	Face to face
7	Scotland	Single fa- ther- sole carer	34	5	15	10	Face to face
8	Scotland	With part- ner	missing	3	15	12	Face to face
9	England	With part- ner (full time carer, whilst wife works)	52	6	13	7	Telephone
10	England	With part- ner	60	6	32	26	Telephone
11	England	With part- ner (own son: 13 and step son: 2 both with DMD)	39	1 month	13 (based expe- riences on 13 year old)	1	Telephone
12	England	With part- ner	46	4	8	4	Telephone
13	Wales	With part- ner	missing	N/a	Deceased	N/a	Telephone
14	England	With part- ner	50	4.5	4.5	21	Telephone

<b>15</b>	Wales	With partner	38	4	4	5	Telephone
<b>Mean</b>			48.4 (34-60)	4.8	4.8	11 (1-26)	

Recruitment

Fathers were recruited through national charity organisations: Muscular Dystrophy Campaign; Scottish Muscle Network; Parent Project UK, and the Duchenne Family Support Group.

**Table 2.** Process of contacting participants via charities

	<b>Muscular Dystrophy Campaign</b>	<b>Scottish Muscle Network</b>	<b>Contact a Family</b>	<b>Duchenne Family Support Group</b>	<b>Parent Project U.K.</b>	<b>Snowball technique</b>
<b>Method of contacting participant</b>	Initial promotion of the study via an advocate at a national meeting  Distribution of packs via care advisors  Advertising in 'DMD News'  Distribution of flyers at Scottish muscle network meetings	Leaflet distribution/ word of mouth at meetings	Advertising of project in e-newsletter	Personal request from Chairman of DFSG, distributed via email network and DSFG newsletter	Distribution of packs to participants with cover letter from PPUK	Contacts made via suggestions of people recruited
<b>Number recruited</b>	N=26	N=5	N=0	N=12	N=4	N=3

Data Collection

Interviews were conducted between May and September 2007. Eight interviews were conducted face-to-face (average 1.4 hours), and the remaining seven by telephone (average 45 minutes). Semi-structured interviews concerned experiences and perceptions of specific areas including diagnosis, coping/adjustment, involvement, support, needs and services. To meet study aims, Grounded Theory (Glaser & Strauss, 1967; Charmaz, 2006) was considered the most appropriate analytic approach allowing a bottom-up method to make meaning of fathers' experiences, whilst promoting theory development. Grounded theory methods (Charmaz, 2006), therefore, facilitated the development of a framework from which to understand participants' perspectives.

Using a Constructivist interpretation of grounded theory (Charmaz, 2006), text was coded to form core categories, in order to generate key themes. As themes were identified, a coding frame was developed and expanded, leading to categories that illustrated key findings. This method of continual comparison allowed evaluation of themes as they arose, and consideration of developing themes in light of new data (Pidgeon & Henwood, 1997). Attempts were made to address 'verification strategies' as outlined by Morse et al (2002), including methodological coherence and development of a dynamic relationship between sampling, data collection and analysis, theoretical thinking and theory development. A reflective diary also allowed identification of initial thoughts, considered as the initial stage of data processing and providing context for analysis (Etherington, 2007).

Ethical Approval

Ethical approval was obtained from the Psychology Ethics Panel at Queen Margaret University, Edinburgh, Scotland,, in February 2007.

Findings

Four key themes were identified: 1) loss and acceptance; 2) support versus isolation; 3) the fight for resources and 4) race against time. The following symbols are used: Interview: I and Written Account: W.

**Table 3.** Themes and sub-themes

<b>Main theme</b>	<b>Sub-themes</b>
<b>Loss and acceptance</b>	Loss Expectations Guilt Adaptive coping and acceptance versus mal-adaptive coping
<b>Support versus isolation</b>	Identity issues Strained friendships Family/marital stress Barriers to involvement

<b>The fight for resources</b>	Frustration Spare part/exclusion Needs and suggestions
<b>Race against time</b>	Images of next stages: transition to adulthood: comparison with other children Deterioration and making the most of life Decisions Talking about death

Loss and Acceptance

This theme concerned fathers’ reactions to their son’s condition, where several losses were experienced. Impact of diagnosis was often framed within the context of previous hopes and expectations for their son’s future and the difficulties in realising these would not be achieved. “You have all these aspirations for your son, and you don’t know until he is actually diagnosed, that he would never really kick a ball. You know, eh, and that hurts because you feel they’re losing out on something and the father’s losing out on something as well” (I: 3).

Transition periods, such as teenage years, were a major challenge for most, as it seemed to represent their son being ‘left behind’, adding to further perceived loss as increasing disability was highlighted in light of increasing independence of other teenagers. Issues of guilt underpinned some participants’ reports of the impact of DMD on family life. This was apparent within various contexts, including diagnosis and restrictions on boys’ and siblings’ quality of life. Also, through genetic issues that affected the wider family, for example, in relation to grown-up daughters’ relationships and mothers’ guilt due to their carrier status. Acknowledging guilt and removing blame, was necessary to move forward as a family in dealing with the condition: “Because it doesn’t come from men... she feels it’s all her fault...because it’s her genes that’s damaged” (I: 6).

Adjustment involved altering expectations held prior to diagnosis, being realistic and accepting no one was to blame, allowing fathers to adopt a positive attitude. “I got the advice from a colleague to say ‘no one’s to blame’. When he said that it was freeing” (I: 4). Those who grew to accept the situation described attempts to focus on the positive and to give their child the best experiences of life. In time, fathers described a need to deal with the deteriorating condition. The degenerative nature of DMD served as a constant reminder, with fathers reporting adjustment in light of this as an ongoing, or impossible, process. One father described a phenomenon he termed ‘issue fatigue’. This captures many of the views of fathers in relation to facing ongoing challenges: “Issue fatigue is more a sapping mental state, that I believe others recognise as being simply a perpetual stream of things to deal with...the shifting sands of DMD” (W: 18). Frequently expressed was a need to appear to be coping, whereby fathers concealed their distress, in contrast to how they actually felt.

Support versus Isolation

A continuous sub-theme of identity issues, both as a person and as a father, appeared to underpin fathers’ experiences of readjusting expectations in light of diagnosis, to reappraisals of their

'father/friend/partner role' and the need to adopt a protective attitude on behalf of the family. One father felt the diagnosis had changed his perception of others, and his own character, whilst others commented on general loss of friendships. "I've found now that I have the whole world on my back, there's not many [friends] around anymore....That's what this condition has done, it's made me so protective of my family that people who I can't rely on, I've dropped them because they've done the same to me" (I: 6).

A sense of isolation linked to a lack of opportunity for fathers to seek support and talk about issues affecting them. With friends, most fathers did not generally talk about their son's condition, and their social networks generally appeared not to encourage this. "Fathers tend not to interact or seek out other fathers. There doesn't seem a need to interact with other DMD dads. You can do it via the internet" (W: 13). One father described a general avoidance, on a par with that of bereavement, on the part of his friends to discuss the condition, and the difference between his friends' reactions compared to his wife's friends: "It tends to revolve around mothers. I mean friends, the first thing they said when they found out is 'how is [wife] taking it?', no-one ever says 'how's [father] taking it?'. They tend not to talk about it at all, my friends don't. I mean, the girls do [wife] and her friends. I suppose girls are more open and used to discussing things. But nobody speaks about it, nobody mentions it. I certainly don't....I suppose it's a bit like somebody dies in the family and you just don't mention it" (I: 9).

Although fathers shared mothers' concerns, their responses and coping strategies differed in some ways. A number of fathers talked about differences in coping within the context of gender, and many knew of families who had split as a result. Often, one partner would want to talk about DMD, resulting in conflict when their partner avoided, or discouraged this. "If one wants to let it out and the other wants to bottle it up, then you've got a bit of a mix up" (I: 13).

Although the majority described being involved with their son, an issue for some was a sense of detachment from certain aspects of the child's life. Most fathers commented that being involved was important, but also said they felt there were barriers to becoming more involved. A sub-theme of exclusion underpinned this theme. Fathers tried to be involved but did not do enough; although they were willing, they were unable, due to work commitments.

### The Fight for Resources

There was a roughly even split between those who said they were satisfied and unhappy with social and general medical provision. Often, it was felt that support was patchy, due to DMD being relatively uncommon in general practice. As most doctors see only a couple of DMD cases in a lifetime, fathers said they often felt they were teaching the professional and frustrated at having to do this with new staff. For instance: "What we've had to do is to educate people we're talking to" (I: 1).

Fathers repeatedly reported fighting for their sons, often as part of their 'duty' to ensure the best possible care. Constant chasing and delays reportedly led to feelings of lack of control. The importance of having a good relationship with professionals was reported by a number of fathers. "If any parent involves themselves, professionals tend to welcome that. You have to be approachable for the relationship to work" (W: 38). In terms of suggestions for improvements, fathers preferred profes-

sionals to be honest and clear about what they could achieve. In this context, the need for others to acknowledge the time limitations of their sons' life-span was important. "It's alright for them saying 'we can get that in six months', but six months is a long time in a boy's...we have to have it now" (I: 3).

Dealing with re-evaluating expectations and knowing how to move forward, was also mentioned in terms of support needs. Specific times where fathers felt extra support was required were diagnosis, times of change and coping with associated feelings of helplessness/loss of expectations. A key factor included wanting to know what they would be able to do with their sons, instead of limitations associated with DMD. "Fathers need to know what they will be able to do with the son, not just left to think on what he'll never do" (W: 26).

Many referred to the strain on relationships, and how support would benefit this impact. Others reported a need to know how to practically care for, and talk to, their sons about DMD. Knowing what to expect, and provision of a schedule of needs/contacts corresponding to each 'stage' was felt to be beneficial. Fathers of older boys felt support needs included the option to talk to someone independently; a need to address boys' frustration at being physically restricted, and somewhere appropriate for boys to mix socially. Fathers of older boys also reported it proved hard to seek guidance. "Our son is 33, Consultants say he's rewriting the test books. We are guiding pathfinders, so it's hard to get help" (W: 1).

A majority of fathers felt services would benefit from a more cohesive system, which would remove the stress of contacting a range of organisations. "A team that works hand in hand to support the family, rather than a collection of individuals pulling in different directions" (W: 2).

Table 4 below summarises a number of key challenges described by fathers, illustrating needs and suggestions for support.

**Table 4. Key challenges: needs and fathers' suggestions for support**

Key challenges	<i>Fathers' suggestions for addressing needs/good practice</i>	
<b>Early stage of diagnosis</b>	Emotional support and confidential discussions one to one  At the early stages of diagnosis, help with fathers' perceived inability to help their sons	Father only support groups  Provide an element of hope  Key person to support and explain what will happen
<b>Acknowledging fathers perceptions of being excluded and encouraging involvement</b>	Ask fathers' opinions  Acknowledge fathers' role and involvement, as well as mothers'	Speak to parents as a whole and don't 'avoid' fathers by speaking through them at appointments  Appointments outside of 9-5pm hours

<p><b>Social activities and support for older sons</b></p>	<p>Address lack of social provision for boys</p> <p>Suitable organisations where boys can go and mix with other people their own, with physical rather than mental disabilities.</p>	<p>Improved access to respite care</p> <p>Provision of clubs where boys can mix with other boys with DMD and those without any health problems</p> <p>For older boys, assistance in finding out about the level of support/financial assistance from authorities</p>
<p><b>Integrated system and professional training</b></p>	<p>Reduce the amount of chasing people up</p> <p>Reduce the need to 'fight' for services</p> <p>A schedule that outlines needs at each stage</p>	<p>Streamline and review processes, to remove stress and facilitate preparation for when deterioration begins</p> <p>More information about processes, planning for mid to long term future</p> <p>Encouragement of young doctors into DMD related fields, to develop understanding and expertise</p> <p>Workshops for the GPs and improved training of professionals</p> <p>Co-ordinated care packages, to promote greater awareness across multidisciplinary teams</p>

Race Against Time

Some fathers described the challenge of DMD confronting their previous concept of an ongoing family line. The limited life span of their son was an underlying theme throughout, with fathers conveying a sense of urgency. This included obtaining best medical treatment and ensuring their son lived as full a life as possible. The need for speed also related to delays with medical procedures, especially when the son's condition was declining. "It took us nearly a year to get an appointment. In that whole year his spinal curvature increased dramatically. He was on the verge of not getting (the operation)" (I: 7). The desire for speed also involved exposing the child to life experiences, often 'cramming in' as many of these as possible, before time ran out. "I get them up at 4am and take them to the airport and don't even tell them. I let them try and guess where they're going. It's like "Disneyland". It's just special little things like that" (I: 6). In relation to accepting their son would die before

them, a reported fear was that of seeing the child in later stages of decline, and concern their son would be rejected when he began to deteriorate. A key challenge was when the child stopped walking, and started wheelchair use. Ongoing deterioration resulted in a continual process of emotional parental stress. “Due to the nature of the condition, it remains continuously the ‘most challenging time’ as the disease progressively steals your child’s physical abilities” (W: 55).

The move from childhood to adulthood was reported to be a challenging milestone, both due to deterioration and also in relation to gaps on services. As their son’s condition declined, watching other children grow up was often described as difficult. Related to the progressive nature of DMD and transition to adulthood, a sub-theme included decision making. This was in light of deterioration, in terms of who led decisions involving treatment, and the process of decision making. Rapid decisions were often required, in the face of time restrictions of the child’s life. Joint decision making with the child in relation to operations such as spinal fusion and Achillies tendon release, was important for fathers. Making treatment decisions was often described as challenging, as there were many factors to consider, including child’s quality of life.

The final sub-theme concerned death issues. A number of fathers reported finding it difficult to talk about death with the child, sometimes expressing relief that this was avoided or dealt with by the mother. It was also difficult wondering how much the child knew already, and fearing having to face the topic where fathers did not feel equipped or ready to discuss. “The other problem I avoid basically is...dying. I just wouldn’t know what to say. I’d be like ‘uh-oh, it’s that time” (I: 5). A number reported dealing with death related queries directly. In these cases, the importance of being honest, and dealing directly with questions, was emphasised.

For some, there were issues in knowing how and when to tell their son the prognosis. Often, this was led by the child initiating the discussion. “He said, ‘am I going to die young?...I went ‘everybody is going to die, anyone might die tomorrow or be here in 100 years” (I: 6). Accepting the fact he would lose his son, and viewing any time with him as enriching, was described by one father of a young son. “The bottom line is if [son] dies, my life will be richer for knowing [son] the way he is” (I: 4).

## Discussion

This is the first known identifiable study to investigate the experiences of fathers of sons with DMD. The qualitative analysis illustrated the emotional impact of parenting a son with DMD. All experienced the progression of the condition at different stages, with a range of reactions from those who coped well to those who found most days challenging. Fathers described an array of perspectives, however, a number of common themes linked their experiences. The first major challenge was dealing with diagnosis, particularly revising previous expectations held. This involved acknowledging loss of father-son activities hoped for and parenting ideals held. At this time, anger, frustration guilt and shock, similar to previous findings (Webb, 2005; Buchanan et al, 1979) were reported, along with a perception, for many, of having received poor information or not being able to understand information received. This finding supports Firth et al’s (1983) study of DMD parent’s experiences of diagnosis, where one third were not satisfied with how diagnosis was disclosed. Around this time, professionals’ attention may be focused on mothers and children, and fathers may feel a sense of expectation to be strong for others.

As with Kornfeld & Siegel's (1979) reported 'cycle of loss', an underlying theme of loss, due to limited life-span, was obvious throughout descriptions. In addition to areas previously described, as with Lee et al (2006), this extended to re-evaluation of previous expectations for continuing the family name.

Some lived in 'anticipation' of next stages and felt unable to become too close to their sons as a possible means of self-protection. In keeping with Kornfeld & Siegal, (1979), a key factor may be that boys look normal in their younger years, and loss of function is slow. Absence of boys' friendships also contributed, with fathers often feeling helpless at sons missing out. Adaptive coping was achieved through proactive attempts to make the most of life, whilst not looking too far ahead. Many coped well, maintaining hope for a cure and using charity work or fundraising as both a distraction and a coping mechanism. As also identified by Erby et al (2006) in discussions of advanced care planning with DMD parents, maintaining hope was important and it helped when professionals provided this, whilst remaining realistic. Decision making surrounding treatments was a cause of stress, worsened by conflicting advice, unpredictable gain and a perception of time running out and therefore pressure to decide between options.

Many moved forward after an initial mourning period and coped through practical efforts with DMD campaigns. Fathers sometimes felt isolated, both from routines and in relation to interactions with professionals. Complete adjustment was often described as impossible due to constant changes associated with DMD, leaving no time to 'recover'. In contrast to Buchanan et al (1979), and Chen et al (2002), coping strategies including self-blame, wish-fulfilling fantasy and 'magical thinking' were not described.

However, defensive coping mechanisms reported as attempts to cope, included withdrawing, or working overtime to avoid family contact. Most were realistic, however, often made attempts to over-compensate through providing 'amazing' experiences their son would remember. This appeared to be a form of over protection, also found by Kornfeld and Siegel, (1979). Coping was generally described in terms of being less emotional and more practical than the mothers' care role. There may be a perceived expectation for fathers to attempt to counteract mothers' more emotionally focused approach, as previously described (McNeill, 2004).

Friendships were described as an important support, and in a number of cases these had been affected by fathers' reactions to the diagnosis. Fathers described the whole family as affected, including maternal guilt, testing daughters for the gene and problem behaviour from siblings due to attention placed on the child with DMD. Consistent with findings of Firth et al (1983) and Fitzpatrick and Barry (1986), communication difficulties emerged as an important area for fathers, also leading to challenges within relationships, where lack of agreement occurred, or where there was no desire to discuss issues on behalf of one partner. In line with previous work (e.g. Pelchat & Perreault, 2003) interviews identified that coping dissimilarities often exacerbated problems within the family.

Similar to Erby et al (2006), avoidance of emotionally sensitive issues was reported. The present study highlighted communication issues with sons, in particular discussing issues surrounding death, and lack of awareness of how much the child already knew, were causes of distress. Witte

(1985) previously identified problems regarding discussing death issues in DMD families. Knowing how to approach the topic and how best to deal with it, emerged as an important need. The significance of the sex of parents and awareness of the dying child is understudied, with authors suggesting research may guide care efforts to promote well-being (Hinds, 2007).

Although cases of excellent practice were reported, some felt services did not account for families' let alone fathers' needs. Two key issues arose: fathers felt isolated from involvement, and partnerships and communication with professionals could lead to frustration. The need to protect and fight was repeatedly referred to, and without understanding this reactive expectation, professionals may view some fathers as aggressive or difficult. As with Fitzpatrick and Barry (1986), communication with both professionals and within the family was a key issue. Similar to research investigating the impact of a genetic x-linked condition Allport Syndrome, (Paljari & Sinkkonen, 2000), having to constantly explain DMD specifics was stressful. Research has previously indicated that health workers may not acknowledge parents' need for information about the implications of the condition (Perrin et al, 2000). As this study demonstrates, acknowledgement of the impact of treatment delays and time scale was important, in light of fathers' heightened awareness of their sons' limited life span. Research in the field of childhood cancer has shown that at later stages, more detailed information is required to steer parents through treatment procedures (Earle et al, 2007).

Negative experiences included a feeling of being viewed as surplus to requirements by staff, perceived as having less involvement than mothers and perception of receiving a lower quality of service without a fight. Dissatisfaction with support and interactions with multiple agencies had an impact on levels of distress. Consistent with findings here, previous work has demonstrated such a lack of awareness amongst providers, surrounding the impact of emotional issues on parents (McKay and Hensey, 1990).

There was frustration at the lack of father-related service awareness. Specific times where this was deemed relevant included post-diagnosis, when decision making, and as boys reached adolescence. Additional needs included provision of optional emotional support to deal with diagnosis, inability to 'mend' the situation and advice about talking to sons about DMD. As with Firth et al, (1983), a number of fathers felt they had not understood or processed information given by professionals. This was often due to heightened emotions surrounding interactions with medics. This is consistent with Chen et al's (2002) finding that fathers needed more help from resources and information.

Fathers also worried about transition from child to adult services and lack of opportunity for sons to attend social activities where they could be actively involved. Frequently they expressed need for a more cohesive service with one contact point. Previous work (Heller & Soloman, 2005) found that consistent staff and co-ordinated continuity of care results in less anxiety in parents and a belief the child is receiving quality care. Such continuity was lacking in the current study, resulting in increased levels of frustration and 'chasing' services. A further need was to know they were not alone in their situation. Father only support groups were suggested as a way of meeting needs. Fathers have previously demonstrated high stress in relation to perceived incompetence (Dellve, 2006). As with McNeill (2004), fathers in this study often demonstrated strength for others and often relied on self-support strategies. Many described losing supportive networks, sometimes due to their need to spend time with family.

Fathers' reluctance to seek emotional support has previously been described (e.g. Pelchat and Perreault, 2003). Researchers have suggested fathers are at risk of isolation due to lack of social support and a need to be in control (Sabbeth, 1984). It has been suggested that the social network is potentially a source of emotional burden (e.g. McNeill, 2004), for some, perhaps leading some fathers to isolate themselves to prevent this. In the current study, isolation and loss of friendships were key issues. Similarly, Firth et al, (1983) found that social isolation for both parents and son was a main concern. Further, this was also associated with an increase in child's emotional problems. These findings echo previous work with parents of a child with cancer, where support variables accounted for increased levels of father but not mothers' distress (Hoekstra-Webers, 2001). In terms of personal support, most stated their partner and immediate family provided support with needs met often within the family. Sometimes this caused problems, for example, when reluctance of one partner to discuss ongoing issues, led to lack of opportunity to acknowledge the impact of DMD.

Similar communication problems were identified by Fitzpatrick and Barry (1990), and highlighted as a key stressor within families. Results show that perceived availability of social support in accordance with relevant needs is an important issue for fathers. Carers with more support are more able to use adaptive coping strategies and meet psychological needs (Love et al, 2005). Although social networks provide emotional support (McGarry and Arthur, 2001), demands of caring for a son with DMD may impact on these relationships.

### Conclusion

The study highlights the importance of redressing the neglect of DMD in the psychological research literature and the need to promote inclusion of fathers in particular. Consistent with previous work (Raina et al, 2004 & 2005; Hinton et al, 2006; Chen, 2008) results suggest efforts aimed at supporting parents to cope with boys' adjustment at key stages, alongside provision of support integrating practical strategies for fathers to promote adjustment. As DMD is one of the most common childhood neuromuscular disorders, it has been suggested that attention be placed on the implications for all who are affected (Morrow, 2004), as boys are now living longer.

A need is identified for bio-psychosocial interventions, acknowledging fathers' needs, role, and involvement in their child's condition. Alongside consideration of the family, the psychosocial impact for fathers should be acknowledged as being equally important to dealing with physical issues surrounding DMD. Professional awareness is needed of the emotional implications, and issues fathers face.

### Contribution

This study has identified issues for fathers in caring for a son with DMD. Barriers have been uncovered, along with indication of stages of greatest support needs. By providing a person-centred approach to understanding fathers' perceptions and experiences, professionals might anticipate possible reactions, specifically issues surrounding loss/expectations; involvement and withdrawal from social support. Family interventions (e.g. Fiese, 2005) could encourage mothers' understanding of the importance of paternal involvement. Due to the progressive nature of DMD, anticipatory guidance could be available, with support at critical periods. In relation to coping resources (e.g. Lazarus,

2000) maintaining hope may be essential. Fathers echoed this need for hope, often in light of professionals not wishing to be overly optimistic. Findings emphasise a gap for person-centred interventions, acknowledging psychosocial impact alongside medical intervention with the child.

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