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'More than a just a physical condition' – recognising the educational and emotional needs of children and young adults with duchenne muscular dystrophy

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ABSTRACT

Advances in medical care have seen children and young people with rare and life shortening conditions, living longer. This is the case for those living with Duchenne Muscular Dystrophy, whose life expectancy has doubled over the last few decades from around 20 to 40 years. Improving care has tended to focus on the physical aspects of the condition, rather than on wider psycho-social needs, such as social, cultural, psychological, educational, and emotional needs. Individuals with DMD are likely to have higher rates of neurodivergence and mental health diagnoses, and this, coupled with increased life expectancy, requires an urgent focus on how schools and colleges support the non-physical needs of pupils with DMD. We discuss existing research on DMD and education, before reporting findings from a small-scale mixed-methods study that explored parents views of their children's experiences in education and that of two adults living with DMD. The findings revealed three main themes: lack of understanding of non-physical needs; lack of support and under-resourced systems; and strategies that work – a hopeful approach. We conclude that established educational and emotional aspects of DMD are often unacknowledged in schools and that ableism and societal assumptions about lifespan can affect education provision.

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Introduction

This article reports the findings of research with parents of children and young people with Duchenne Muscular Dystrophy (DMD) and a small number of adults with DMD that focused on the educational experiences and support for children and young people with DMD. As we later discuss, there is limited research that explores the experiences of school and further education for children and young people with DMD (Soim et al. 2016). It could be argued that one reason for this lack of focus, has been due to the life-shortening nature of this condition which historically meant that children would not reach adulthood. This was noted over 30 years ago by Leibowitz and Dubowitz (1988) who argued that; 'often education is seen as a preparation for

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adult life, and for DMD children the whole process sometimes may seem rather meaningless' (p 586). Due to advances in medical care however, most young people with DMD, can expect to live into their fourth decade (Landfeldt et al. 2020). It is therefore more important than ever that young people with DMD are provided with opportunities to achieve their full potential at school so they can live meaningful adult lives.

DMD is a rare genetic condition that affects one in 3,500 males, and is characterised by progressive muscle atrophy, including the heart (Birnkrant et al. 2018). As a consequence, most young people with DMD become full-time wheelchair users around the age of 13, and typically begin to use ventilation in their teens and early twenties (Bushby et al. 2010; Landfeldt et al. 2020). We acknowledge here at the outset, the emphasis in both research and clinical practice tends to be on the physical aspects of this condition, which can often feel deficit based and at odds with the intended focus of this discussion, which advocates for a holistic approach in meeting need. Indeed, concerns have been raised that the wider needs of children with DMD, which may include psychological, social, cultural and educational needs, has been neglected (Morrow 2004; Setchell et al. 2022). Setchell et al. (2022), writing from a Canadian perspective, argue that the focus on the biomedical in DMD and Becker MD (a similar condition) has come at the expense of the 'human aspects of care' including psychosocial needs, and considerations of finding fulfilment in life.

We would argue therefore, for a wider understanding of the issues children and young people with DMD may face within educational settings. This is of import, not least because of the need for educational institutions to be inclusive, but in relation to DMD, there are often associated additional educational needs, which include neuro-divergent and mental health conditions. Indeed, as Linertová et al. (2019) have noted, there is an urgent need to undertake research on the educational experiences more generally for those with rare conditions, including DMD, given the prevalence of neurodivergence within this population. The study therefore aimed to explore:

- (1) What are the specific special educational needs that may impact children with DMD at school
- (2) How educational settings can best support children and young people living DMD and additional educational needs

The discussion begins with the context of special educational needs and disabilities in England.

Context - special educational needs in England

The Special Educational Needs and Disability Code of Practice (SENDCoP) (2015), applicable to all young people in England aged 0–25 years, categorises Special Educational needs and disability into four areas:

- Communication and Interaction
- Cognition
- Social Emotional and Mental Health

- Physical Disability

These fixed categories, alongside disablism, could mean that schools struggle to understand the lived experience of disability or offer holistic support. An Education, Health and Care Plan (EHCP) is a statutory document that sets out the Special Educational Needs of a young person, bringing together agreed provision from education, social care and health services (DoE&H 2015). The introduction of EHCPs and the SENDCoP (2015) promised higher aspirations and less confrontation for families, with an expectation that young people and their parents/carers would be involved collaboratively in the process (DoEandH 2015, 11). It falls on the Special Educational Needs Co-ordinator (SENCO) at school to monitor the plan, and despite the need for multi agency input, these plans have remained predominantly educational (Boesley and Crane 2018). SENCOS have also reported a lack of confidence in their knowledge of SEND due to the complexity of their role combined with lack of time (Smith and Broomhead 2019). This has resonance for DMD, which, as a rare condition, means schools may not have encountered a young person living with the condition before. Given these complexities, a wider understanding of the condition within school and other educational settings is urgently required.

DMD and School

It has been noted that there is very little literature that focuses specifically on DMD and school (Soim et al. 2016). The Clinical Care Guidelines for DMD (Birnkrant et al. 2018) include educational needs within the category of 'psycho-social care' which combines all non-physical needs associated with DMD. These needs include neuro-divergent conditions such as Autism Spectrum Condition(ASC), Attention Deficit and Hyperactivity Disorder (ADHD), challenges in developing academic skills due to cognitive, working memory and phonological difficulties as well as mental health diagnoses such as anxiety, depression and OCD. The phrase "psycho-social care' is therefore potentially confusing, not least as it covers a wide range of needs, some of which fall outside of medical domains. This article therefore focuses on aspects of psycho-social care that affect education and school.

Literature focused on schools and DMD fall into three broad areas: firstly, research that investigates developmental and cognitive needs in children; second, designated educational support, and third, studies focusing primarily on other topics but cover school experience more generally. There is a wealth of papers identifying developmental and cognitive deficits (see for example, Hinton et al. 2000; Henderson & Vles 2008; Ricotti et al. 2016), which remain broadly located within a biomedical model and are predominantly quantitative. There is one published school intervention that has supported difficulties in reading and literacy development (author 2014). Although this area is important, we do not propose to explore this literature in depth here and we note the deficit language utilised.

The second broad area concerns the amount of support offered at school. An international study looking at the neuro-developmental needs of young people with DMD including 133 children with DMD up to the age of 9 years noted that 63% of families reported their child did not receive any support at school compared to 27% receiving classroom services (Thangarajh et al. 2018). However, in a US study of 179 pupils with DMD that looked at a wider age range, 60% of participants used an instructional assistant

(teaching assistant) and this became more prevalent as the young person got older and became non-ambulant (Soim et al. 2016). This could suggest that focus remains on the physical needs of young people as their support increases and their physical abilities deteriorate with age.

In terms of the third broad theme, that of school experience, the literature remains scant, with most information coming from studies that are not specifically exploring school. School attendance has been noted as good (at 90–95%) by two European studies (Lopez-Hernandez et al. 2014; Magliano et al. 2014). This aligns with the only qualitative study we could find specifically exploring school experience for children with DMD which included 33 children with DMD in India. This reported that despite a lack of basic school facilities as well as curricular and extra-curricular exclusion and poor teacher attitudes towards disability, children with DMD still prefer to attend school so that they can be ‘relieved from their health-related thoughts’ as well as develop important social and emotional skills for life (Sadasivan et al. 2021, 27).

Findings from a recent qualitative study (Glover et al., 2023) found that experiences at school were varied, with some young adults reporting difficulties fitting in at school, lacking confidence, and feeling that teachers’ had low expectations of their abilities. Overall, we concur with Soim et al. (2016) who note that despite established learning challenges that can be associated with DMD, very little has been published about how children with DMD experience school and how they are supported. The next section goes on to explore methodology.

Methodology

This study utilised a mixed methods approach, using two data gathering methods, a questionnaire and focus groups. The quantitative element of the design was necessary to understand the wider needs of children and young people living with DMD and how these were supported through school. The research approach overall, relied more heavily on qualitative epistemological and ontological underpinnings however, as the research aimed to understand individual feelings and perceptions about SEND and DMD (Coe et al., 2021). Furthermore, as the prevailing epistemological assumptions that tend to underpin research on DMD are largely based on knowledge and approaches from the medical and scientific community, it was important, and indeed urgent, to include and centre the experiences of families and to some extent adults living with the condition. A further influence on the methodological predisposition of the research was one of ‘researching with’, rather than ‘researching on’ (Moriña 2018) and ensuring data gathering approaches

were, as far as possible, participatory, inclusive and emancipatory. Additionally, it is important to note that two of the three authors have personal experience of DMD, the first author is a mother of a young adult with DMD, and the second is living with DMD. The researchers were therefore able to play an active role in the (re)construction of knowledge (Braun and Clarke 2019) as they brought their expertise of lived experience to the research process, in an area that is often dominated by professional medical thinking and priorities.

Table 1. Focus groups.

| Group Number | Age of children/person with DMD | Number of participants in group |
|--------------|---------------------------------|---------------------------------|
| Group 1 | 3 - 6 years | 5 |
| Group 2 | 7 - 12 years | 8 |
| Group 3 | 7 - 12 years | 10 |
| Group 4 | 13 - 18 years | 4 |
| Group 5 | 18 years + | 2 adults with DMD and 2 parents |

Methods

The research design had two stages. The first stage included participants undertaking a brief online questionnaire, which centred on non-physical needs and any support they received with regard to this need within schools. There were two questions which allowed for free text. Five online focus groups were subsequently organised, which were arranged according to the ages of the person with DMD, acknowledging age-related expectations in education as well as the reported preference of parents to talk to other parents who have children of similar ages (Poysky and Kinnett 2009). The groups were organised as follows in table 1:

Participants

A purposive sampling approach was utilised, inviting parents of children and adults with DMD, as well as adults with DMD, to complete the questionnaire and then take part in online focus groups via the social media platforms of the UK charity Duchenne UK. Thirty-one individuals volunteered to participate in the study, which consisted of 27 parents of children with DMD, two parents of adults with DMD, and two adults with DMD. 87% of Focus Group participants were White, 16% Asian or British Asian, and 87% had a Diploma in Higher Education or above. All participants lived in the UK and all gave written consent to take part. All names have been changed to protect the anonymity of participants and issues of privacy were further considered. For example any information that could possibly identify individuals, was removed, which was important given the rare nature of the condition. Ideally, we would have spoken to children with DMD, but as an unfunded project this proved logistically difficult – nonetheless two adults with DMD were engaged in the research project – however future research should certainly focus on the views of children and young people with DMD.

Data analysis

The questionnaire was analysed using simple statistical analysis and a reflexive thematic analysis (RTA) was used to analyse the free text from the questionnaire and qualitative data from the focus groups. Thematic Analysis has become firmly established in qualitative research for almost two decades (Braun and Clarke 2006, 2021; Clarke and Braun, 2018) and RTA specifically highlights the active role of the researcher in analysis and knowledge production (Byrne, 2022; Braun & Clarke, 2021). Initially, the first author looked at the qualitative data from the questionnaire and the focus groups to notice any initial themes. This was useful as some of the questionnaire's free form data helped to confirm some of the patterns emerging in the focus group data. The data was then combined to construct codes that initially fell broadly within the areas of needs, support, challenges, and solutions. These descriptive codes from the combined data were discussed with

the second and third authors and developed into latent codes to look for any underlying assumptions (Byrne, 2022). All authors were reflexive in their reading and discussion of the data to ensure participants' voices were central to the generation of the themes across the dataset. From this process three key themes were constructed.

Ethics

The research was given ethical approval by the University of X ethics committee where the first author was employed. As with all research processes, attention was paid to issues of informed consent, anonymity, privacy and avoidance of harm. It was recognised that focusing on challenging events and experiences in their children's lives, or their own, may cause distress, so a debriefing protocol was out into place if required.

Findings

Quantitative findings

We noted the high prevalence of co-existing conditions within this small cohort as is shown in Figure 1. This is important to highlight as it confirms other research that identifies links between DMD, neurodivergence and mental ill health. We also noted that 36% of the children and young people had more than 1 diagnoses. The impact of these additional needs emerges in the qualitative findings.

The discussion now moves on to consider support which Figure 2 highlights.

As it can be seen, within the school context, the biggest provision of identified support within schools was teaching assistants, followed by literacy intervention and speech and language therapy. This is further elaborated upon in the qualitative findings.

Qualitative findings

Findings are structured into three main themes with subthemes as documented below.

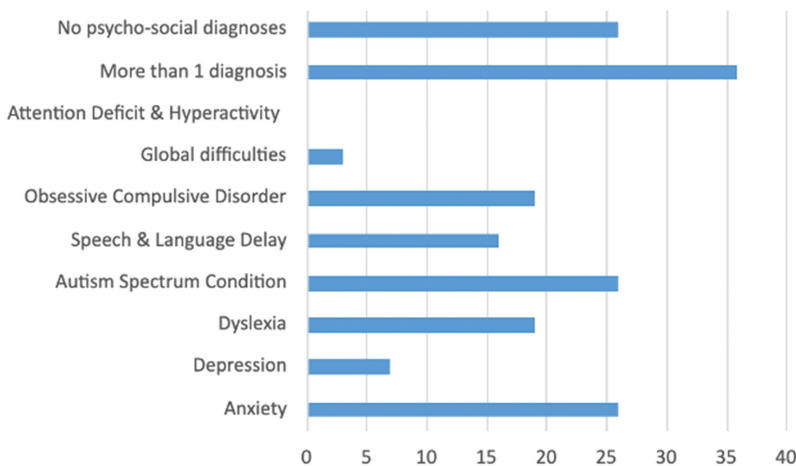


Figure 1. Self-reported diagnoses from initial questionnaire by percentage of group $n=31$

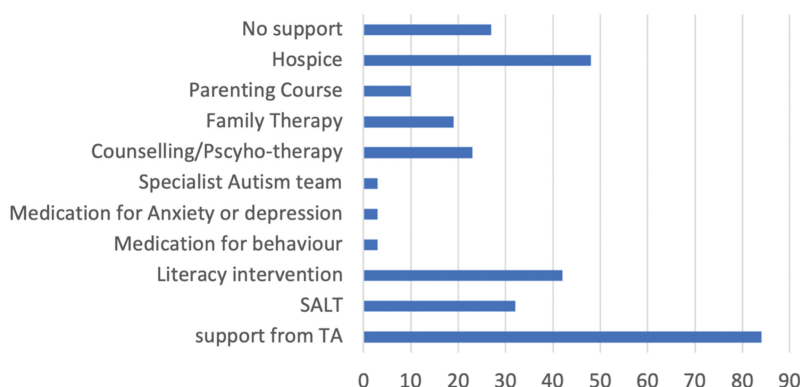


Figure 2. Support/interventions offered by percentage $n=31$.

Theme 1 - not just a physical condition

Participants shared concerns around the lack of acknowledgement of the non-physical needs linked to DMD which could be complex. This is also highlighted by the quantitative findings that show over 20% of participants reported a diagnosis of Autism Spectrum Condition(ASC) and Anxiety, and over 30% reported more than one diagnosis.

Issues linked to a diagnosis of Autism Spectrum Condition (ASC)

Behaviours associated with ASC were discussed in all groups, such as repetitive behaviours, anxiety and sensory issues. Parents identified rigidity around food choice, the need for clothing to be put on in a particular way and regular 'meltdowns' where their children became overwhelmed with their surroundings. In relation to the impact of ASC within school, it was felt that the schools did not accommodate these differences and viewed children as 'difficult' rather than neuro-divergent. As Stephanie reported:

The main anxiety I have had not been the mobility issues - it's more than a physical condition. For us it's all about the learning and the behaviour side, as he has learning behaviour and autistic traits and definitely OCD, and getting support for that. ... I think the understanding that Duchenne does come with these additional needs is something there is a gap on. (Group 2)

Michelle similarly commented; *'It's not the DMD that's difficult but the autism'*. and the lack of appropriate support given to her son at school. She commented:

He got a detention over lunch time for fiddling with things because he likes to fiddle with things and he missed his lunch - he didn't have any food. It causes so much upset for me ... I want people to know about him before the horse has bolted. (Group 2)

This suggests that schools may not be making reasonable adjustments for behaviours that can be associated with neuro-divergent conditions.

Emotional and mental health

Emotional needs were particularly discussed in Groups 2 and 3 where children were coming to the end of primary school or in early secondary school. In these cases, teenagers with DMD often felt isolated from their friendship groups as their condition

progressed, and for those using wheelchairs, were presented with disabling access issues. Kim reported on the widening gap between her son and his peers as he transitioned from primary to secondary school, She commented:

L has just gone through a bit of a realisation that those he called his friends in primary school are no longer there. All through lockdown, they were online with him gaming and of course lockdown's gone and so have his friends. They've gone back to their schools and their lives outside. They go out on their bikes and L is never invited and can't keep up. (Group 2)

This exclusion, often caused by a lack of wheelchair accessibility, not only affected their sons at school but the whole family. As Lynne, a parent in Group 3 reported *'we can't even go and visit Grandma anymore'*.

Some parents in these groups reported that their sons experienced serious mental health challenges and two reported that they had often received phone calls from school about their sons' suicidal thoughts. One parent of a young person in their mid-late teens reported that their son regularly said things like, *'What's the point of being alive', 'I'd rather be dead'* and another parent of an adult with DMD reported that her son had asked when he was younger *'what would happen if I drove my wheelchair down the stairs?'* Although comments relating to suicidal ideation related to a small number of participants, poor mental health was something that adversely impacted the lives of some young people and their families.

Several parents suggested that deterioration in their young person's mental health as they became a teenager was caused by existential fear as they began to understand the implications of their condition. For example, Katy commented:

(he) was the life and soul when he was younger and a real cheeky chops, always the one telling the jokes and everything. And then as time's gone on and he's understood more about the condition and what's going to happen then it just seems to have steadily just eaten away and gets him down (Group 3).

Two parents in Group 5, whose young adult children experienced anxiety and depression felt strongly that their sons would have engaged with mental health support more easily if this was something they had experienced on a regular basis. This is illustrated by Julie, who said that her son refused to attend his Further Education college when he was 17, when he began to use a wheelchair: She commented:

... he's not leaving the house ... and he's quite self-destructive with alcohol and things like that you know and he will get himself wasted into a complete oblivion. ...everyone's talking about mental health now aren't they and mental health is about talking isn't it? And if that can be a regular thing from day one it's normalised and then you know they're getting their feelings out . (Julie, mother, Group 5)

David, an adult living with DMD reflected on his experience of school. He commented:

"I did think I would like some mental health support, but it wouldn't do any good now, perhaps in the past. I've found [social situations] quite hard ... if I had had a bit of that support at school ... I think it would have benefited me later in life ... I do have periods of quite low moods really and I find it difficult to try and handle it'.

Julie believed emotional and mental health support should have been an integral part of her son's routine care, could have helped him adapt to using a wheelchair and continue his education. Indeed, the next theme goes on to explore the challenges of accessing appropriate SEND support.

Theme 2: accessing SEND support

Support for children with complex needs does not just come from school but from a range of services within the community that contribute to a young person's Education Health and Care Plan (EHCP). Parents discussed attempts to obtain appropriate support from both school and services, often using words such as '*fighting*' and '*battles*'. Participants discussed the time it took for referrals from school to specialists to occur (if at all). In this study, 76% of participants reported that their children/young people had an Education Health and Care plan (EHCP), and within these plans, learning and mental health needs were noted. Despite this, parents often struggled to receive the provision in the plans. Catherine for example stated:

EHCPs are just not worth the paper they're written on, adding: We're just tired of all the battles (Group 4)

Parents reported that despite having recognised diagnostic labels these were rarely supported by people they deemed appropriately qualified. Therefore, few young people with DMD received specialist intervention, with the most support coming from a teaching assistant (TA) at school.

Some parents also shared how school structures were not flexible enough to meet the multiple needs of their children. Sarah, for example commented:

'In September they're opening a new resource provision at F's school which will be an SEMH (Social Emotional and Mental Health) provision so they will take children who have social and emotional issues. But our children here that access the Physical Disability Unit won't be able to access any resources for the social and emotional support because their needs are seen as just physical . . . it's difficult to get them to recognise those issues outside of just the physical situation (Group 3).

This demonstrates an inflexibility of school systems to acknowledge and support students who experience more than one category of SEND and so essential aspects of educational provision can be missing for these young people. Furthermore, an absence of preparation for life after school was noted as missing for these young people. For example, Mark, an adult living with DMD commented on how he struggled to find the right support after he had left full time education:

'it's particularly after you leave education that you don't have any support at that point, and you're thrown out on your own . . . because it feels like there needs to be some kind of intervention at that stage, when you leave education, to try to set you up on the right track and make it clear how are you can get additional support if you need it'.

Local Child and Adolescent Mental Health Services (CAMHS) were criticised by several participants who reported long waiting lists followed by having their cases closed because their sons would not engage. Additionally, some young people were denied support because they were not deemed suicidal. Furthermore, some parents felt that

mental health services held assumptions about life-limiting impairments that influenced the way in which they interacted with their child. As Duncan, who had a 15 year old son with DMD explained:

We tried CAMHS here in **** and they said, I quote, “we can’t offer anything as we can’t fix the problem!” So because Duchenne has no cure they said they wouldn’t be able to help with any counselling or anything like that because their job is to help people overcome something and then get better and that’s it, rather than help him and us manage it through. (Group 4).

On this note, other parents shared that school had accepted that depression was to be an expected consequence of living with DMD, perhaps highlighting prevailing attitudes about the possibility of having a good life with a disability (Chouinard, 1997, in Campbell, 2009: 5), particularly one involving a short lifespan.

Parents often felt confused as to who ultimately should be responsible for the emotional and mental health needs of their young people, with both local CAMHS and their neuro-muscular clinic unable to communicate with each other. As Duncan, the father of a 15 year old boy said:

‘It’s like a merry-go-round a lot of the time, you’re trying to jump off at the right spot, but they’ll go – no, that’s not us, he needs to talk to them! . . . and then . . . Oh no that’s definitely not us! You need to talk to those people. (Group 4)

This reflects Duncan’s frustration with what he perceived to be a lack of accountability for his son’s non-physical needs. Despite these systemic and structural challenges, many families had nonetheless, developed positive strategies to support their children’s well being, both at school and home.

Theme 3: strategies that work – a hopeful approach

Participants discussed strategies and resources that they felt best supported their sons’ educational and well-being needs, and which could impact positively on their experience of school. Some parents reported benefiting from free counselling at local hospices offered to the young person with DMD as well as the wider family. A small number of families paid privately for psycho-therapy but this was around £100 per session, which most said was not affordable. The adults with DMD reported that they had benefited from counselling at particularly difficult times, and life coaches were discussed as potentially useful. Several parents of children who were in secondary school discussed the importance of their sons having a designated person to talk to at school, stressing that this did not have to be a trained psychologist, but rather someone who could listen and understand. Parents reported the importance of their own extended families, who gave both practical and emotional support, and others spoke about their ‘*Duchenne family*’ meaning other families affected by DMD who they met up with at conferences and who understood what they were experiencing. This was similar for adults with DMD. Mark commented on the need for:

having role models and learning around your peers. I don’t know how you put that into a guideline really, I just feel like sometimes, if there is difficulty, the breakthrough might come from seeing some one else in a similar situation (Mark, adult with DMD)

Establishing and encouraging a young person's interests was viewed as crucial, and activities that a young person could continue with as he grew older and his physical abilities decreased were particularly recommended. This included power-chair football, computer gaming and swimming. One parent, Desi, spoke about how football was his ten-year-old son's '*passion*' and how he had found a sense of belonging in power-chair football because '*everyone's in the same boat*' and that he '*wasn't always the odd one out*' (Group 2). Some families suggested that their sons valued being part of a community where they were not the only disabled young person, and parents commented on the support and solidarity this brought them as well.

Moreover, adults with DMD reported that an important strategy for their mental health in adulthood was finding something meaningful to do, whether it was volunteering, taking part in creative projects or obtaining paid employment, as David commented:

Just having something to get up for and get into, something to research and be excited about and look into. So I think it is having something to look forward to, something that can occupy your time. (Group 4)

Discussion

This study suggests that children and young people with DMD experience a range of challenges that are not always associated with the physical symptoms of their condition and as such, these needs can often feel unrecognised and indeed unimportant. We argue that what perhaps underpins this, is not only a lack of knowledge about coexisting needs but deeply rooted assumptions that are linked to medicalised and personal tragedy ideas of disability. The influence of able-bodied assumptions in schools has been noted by several writers (Florian 2007; Hart et al. 2004). This has been termed the 'normative model of difference' where school structure, curriculum and pedagogy are based around the normative pupil. Similarly, McRuer (2006) argues that 'compulsory able-bodiedness' and the power of 'the normate' negatively impacts the experiences of all disabled people (McRuer 2006). (Chouinard, 1997, in Campbell, 2009: 5) defines ableism as the: 'ideas, practices, institutions and social relations that presume able-bodiedness, and by so doing, construct persons with disabilities as marginalised and largely invisible "others"'. It was clear from our findings that parents felt their children were often marginalised due to lack of inclusive practice at school. Furthermore, children with life-shortening conditions may be affected by 'ableist constructions of time' (Abrams, Abbott, and Mistry 2020), which could influence the ways in which schools and teachers support young people with DMD to prepare for the future. Our findings reflect the impact of ableist systems and attitudes that do not acknowledge the wider needs of young people living with a complex disability. McRuer (2006) argues, however, that by resisting normativity and disrupting assumptions and expectations placed upon them, disabled people find agency and meaning in life. This can be seen in our findings through the ways in which families support their young people to explore and identify interests which give them a sense of self and belonging.

Implications for school practice

Inclusive education means accepting all children and enabling them to actively participate and feel a sense of belonging (Hodkinson 2012). Therefore, schools need to understand the individual needs of the child with DMD and develop ways to ensure they are included. With regard to academic support, as most families in this study reported on the input of teaching assistants (TAs), it is essential that schools offer appropriate training to TAs on how to scaffold learning (Bowles, Radford, and Bakopoulou 2018), and give opportunities for joint working between class teachers and teaching assistants. This must ensure the child with DMD has equal access to a trained teacher. The value of early academic support and confidence cannot be overstated as the adults with DMD we spoke to highlighted the importance of being able to work or volunteer because it offered them meaning in life. Furthermore, spending time discovering what excites and interests children with DMD and using this as a starting point for learning could be key in supporting school inclusion as has been shown in research with autistic children and their special interests (Wood 2019).

With regard to social and emotional inclusion our findings confirm earlier work that shows that it is when children with DMD are struggling to keep up with friends and beginning to lose the ability to walk that they face most emotional challenges (Travlos et al. 2017). In addition to individual mental health and counselling services, schools can support children and young people with DMD further by fostering a sense of belonging. It is important to keep in mind that usual out-of-school activities that can affect in-school friendships such as visiting other people's homes or taking part in activity clubs can become increasingly challenging due to lack of wheelchair accessibility. Support for friendship at school through programmes such as Circle of Friends (Frederickson, Warren, and Turner 2005) and extra-curricular activities and clubs that focus on interests of children with DMD including ones that do not depend on physical strength and dexterity may support inclusion. Underlying all of this is the need for schools to have high expectations and an understanding that life with DMD can be a good life.

Strengths and limitations

To our knowledge this is the first qualitative study with parents of children with DMD and a small number of adults in the UK to focus exclusively on school and DMD, about which there is relatively little published. There are several limitations to this study however. Firstly, as a predominantly qualitative study, the findings cannot be generalised, coupled with the relatively small sample size. As with all research processes, we do not know the motivations for why people chose to participate, perhaps because they have experienced significant challenges, or perhaps feel confident and able to talk about their experiences. A further limitation could be that recruitment through the online platform of one particular charity can mean the exclusion of families with no access to the internet or social media. Finally, as has been noted, the voices of children and young people with DMD is missing, as is the voice of the teacher and other educational professionals, which should be considered as areas for future research.

Conclusion

This is an important and original study building a rich and detailed picture of a wider range of educational and emotional needs that can present in school and how schools can more fully support children with DMD. The questionnaire findings supported existing research that highlights the high prevalence of neurodivergence and mental health issues amongst those living with DMD and the qualitative findings also accord with existing research that highlights particular age-related concerns.

The experience of schooling was not always positive, with the needs associated with mental ill health and neurodiversity not adequately recognised, or supported, alongside the challenges of agencies working together, most notably when ECHP plans are being devised, or indeed, when the promised support is not forthcoming. We also note the lack of understanding amongst school staff, and indeed other professionals within multi disciplinary networks, who lack insight into what it is like to live with a life shortening condition, one that is progressive, and associated with a range of need.

We would argue therefore, for a hopeful approach to education, which is essential to ensure that all people with DMD are supported to have the best life possible. This means psychological and emotional needs are supported at school in a timely way and as a matter of course rather than waiting until a time of crisis. Training schools about the non-physical aspects associated with DMD is essential, as are schools' ability to support the development of skills and areas of interest from an early age. In this way, young people with DMD can expect to achieve interesting and meaningful lives as they become adults, and maximise positive opportunities and experiences.

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