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RESEARCH

'You're Not Taking Us Down Duchenne!' Seeing, Valuing, and Supporting the Resilience of Mothers of Children Living With Duchenne Muscular Dystrophy Through Positive Psychology Interventions

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Abstract

Mothers of young people with the rare, genetic, life-shortening condition Duchenne Muscular Dystrophy (DMD), face multiple challenges and pressures. DMD is characterised by progressive muscle degeneration affecting skeletal, respiratory and cardiac muscles. Many young people lose ambulation during adolescence and may require ventilatory support as respiratory muscle weakness progresses (Birnkrant et al., 2018). DMD can also be associated with other conditions, such as Autism Spectrum Condition, Attention Deficit and Hyperactivity Disorder, dyslexia and poor mental health. Whilst life expectancy has improved, given the rarity and everyday impacts of the condition on individuals and their families, the stress of caring for a young person with DMD can be significant. Not least, the wide range of medical and social care professionals involved, the ongoing struggle to secure care and appropriate resources, and the impact of living in an ableist society. This article documents findings from a small-scale pilot intervention with mothers of children with DMD, informed by positive psychology, which aimed to explore their understanding and embodiment of resilience. The study found that mothers were able to acknowledge their strengths, achievements, and resilience by engaging with positive psychology interventions, whilst recognising that adjustment was not linear. We argue that there is a need for health and care teams to employ a strengths-based approach to support mothers of children with DMD, acknowledging the expertise and experience that mothers can offer. Further, the intervention demonstrated the potential of using positive psychology interventions in workshops for mothers of children with DMD.

Key message

- Positive Psychology interventions have the potential to be an effective support mechanism for mothers of young people with Duchenne Muscular Dystrophy.
- Facilitating opportunities for families to meet families of older children could improve adaptation to the progression of the disease.

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- Health and social care teams, should employ a strengths-based approach when working with mothers of children with DMD, which recognises their achievements, strengths and resilience.

Keywords DMD · Resilience · mothers · Strengths · Coping Skills · Hope

There is limited research that focuses exclusively on the experience of mothers of children who have the rare genetic muscle wasting condition Duchenne Muscular Dystrophy (DMD), with most studies exploring broader parental or caregiver experiences (Donnelly et al. 2022). Furthermore, exploring resilience among carers of individuals with DMD remains limited, despite increasing recognition of the psychological and practical demands associated with caregiving (Glover et al., 2020). Overall, studies published in this area tend towards a deficit perspective and follow a similar trajectory to research focusing on parenting children with other disabilities. Themes include negative impacts on the physical and mental health of carers (Abi Daoud et al., 2004; Domaradzki & Walkowiak, 2024),and the practical burden of caring for a child with DMD, such as the lack of access to community venues and financial strain (Porteous et al., 2021. Stroobach et al., 2023; Landfeldt et al., 2018). The psychological burden has been noted to include negative impact on family members' well-being, feelings of loss, fear for the future, and sadness (Magliano, 2014a; Landfelt et al., 2020; Donnelly et al., 2023; Domaradzki & Walkowiak, 2024). It is acknowledged that there is some research, albeit limited, that highlights the positive impact of caring for a child with DMD, such as offering meaning and purpose (e.g., Magliano et al., 2014b; Pangalila et al., 2012).

In this article, we report findings from an intervention undertaken with mothers of children with Duchenne Muscular Dystrophy (DMD). We piloted workshops that were informed by principles of positive psychology, in order to explore how mothers of children with DMD conceptualise, understand and embody resilience in their everyday experiences of caring for a child living with a deteriorative and life-shortening condition. This takes us beyond a narrative that sees caregiving as always burdensome and stressful, and acknowledges mothers' strengths, knowledge, and resilience. Such an exploration is important for the following reasons: first, there is limited research on resilience and caring for children with DMD (Glover et al., 2020); second, what exists is overwhelmingly quantitative and cannot highlight the nuanced complexities of caring; third, notwithstanding the challenges associated with caring for a child living with DMD, existing research tends to focus on the negative impacts, for example, physical health (Brekke and Alecu, 2023) or mental health (Scherer et al., 2019); lastly, resilience as a construct has centred on individual assets and personal traits rather than on cultural, economic, and social factors that may impede its development (Southwick et al., 2014). It is important, therefore, that a wide variety of professionals who will inevitably encounter mothers of children living with DMD understand the complex terrain that mothers inhabit, in order to avoid pathologising them through deficit-based or tragedy models. Instead, professionals should seek to understand how mothers embody resilience in their daily lives and engage in strengths- and competence-based practices that enhance their resilience.

We centre the research on mothers, rather than fathers, or co-parents, as we note that care of children, particularly those with disabilities, falls disproportionately to mothers (Ryan & Runswick-Cole, 2019; Tomiack et al., 2007).

Duchenne Muscular Dystrophy

DMD is a rare genetic disorder, overwhelmingly affecting males, that is characterised by progressive muscle atrophy, including the heart (Birnkrant et al., 2018). Typically, young people with DMD become wheelchair users around 13 years old and require ventilation in their late teens (Birnkrant et al., 2018). DMD is also associated with neurodivergence, ADHD, autistic spectrum disorder and mental health challenges (Hoskin & Finch, 2025).

Improved medical treatments, including corticosteroids, cardiac management, and nocturnal ventilation, have meant that most young people now live beyond their early twenties, with many expecting to live into their forties (Landfeldt et al., 2020). The improved life span has arguably had a major impact on those caring for people with DMD who are now supporting their children into adulthood, perhaps without expecting to. It is therefore essential now more than ever, that parental, and particularly maternal, caregiver resilience is revisited to best support young people as they live longer. This is particularly true in cases where there is limited social support and where parents are expected to provide prolonged caring duties (Porteous et al., 2021). Parent caregivers have been described as 'lifelong experts' in the needs and experiences of their young people with DMD (Donnelly et al., 2023) acknowledging the essential role they play in keeping the person with DMD healthy and free from illness. Although research is divided on the impact of age on carer burden, several studies have reported increased stress as the person with DMD gets older (e.g. Moura et al., 2015; Yamaguchi et al., 2019), and others have highlighted increased practical burdens (Peay et al., 2016). The discussion now considers the concept of resilience and how this presents in literature about mothers of young people with DMD.

Resilience

Although there is no agreed definition of resilience, it has been noted that the presence of resilience can reduce anxiety and depression and play a protective role in the effects of trauma and stress, promoting psychological adaptation and improved life satisfaction (Joyce et al., 2018). Traditionally, resilience has been viewed as a stable personality trait; however, more recently, it is regarded as dynamic, variable, and multidimensional (Bonanno & Diminich, 2013; Chmitorz et al., 2018). We agree with others who have noted that research should acknowledge the impact of structural inequalities and view resilience as a right, or a civic duty (Ungar, 2008), rather than as a character trait, and those deemed not to be resilient, viewed in a deficit manner. A lack of published strategies to support parental resilience in DMD has been noted (Peay et al., 2016; Porteous et al., 2021), with interventions, if mentioned, discussed only as suggestions for future research rather than as a focus of empirical study (Porteous et al., 2021). A study from the United States with over 200 mothers

suggests that although neuromuscular teams should anticipate an increased practical burden for carers as their children grow older, support for developing resilience that focuses solely on caregiver burden and deficit will not improve mothers' psychosocial well-being (Peay et al., 2016). Therefore, some writers have highlighted the potential of Positive Psychology approaches to foster resilience by highlighting existing strengths and improving perceptions of the impact of DMD (Peay et al., 2016). The discussion now moves on to consider methodology and subsequently, methods.

Methodology

This paper uses an interpretivist paradigm, in particular, interpretative phenomenological analysis (IPA), to explore how mothers conceptualise, experience and embody resilience, after participating in an intervention based on positive psychology methods. We used a Positive psychology construct of resilience because it explores well-being as flourishing, rather than 'psychology as usual' that predominantly looks at deficit and dysfunction (Seligman et al., 2005). Furthermore, we used a multi-dimensional approach to resilience that embeds individual coping and adaptation within a socio-ecological framework, acknowledging the role of individuals and family, community, society and systems rather than just a personal trait (Lomas et al., 2014). We believe, as others have noted (Southwick et al., 2014) that such an approach is crucial to ensuring professionals move away from a deficit-based model of individual coping towards a strength-based model, with the aim of recognising and building on pre-existing strengths. Using double hermeneutic research practices, we sought to co-create the meaning of mothers' experiences (Smith, 2004), which were essential to this study, with a need to centre the experience of caring for a child living with DMD. Real-world consequences from research depend on its epistemological assumptions and thus 'which version of knowledge is given privilege' (Mertens & Wilson, 2012, p. 170). In the case of a condition like DMD, epistemological assumptions are usually based on a medical professional's perspective and often fail to centre user experience or utilise coproduction philosophies. To address such concerns in DMD research approaches, it is important to note that the first author is the mother of a young adult with DMD and can therefore offer insider knowledge and experience that has traditionally been missing in DMD research. On the other hand, it was acknowledged that her insider experience could colour her view of the data and so discussion with the research team through the various stages of the research process was crucial in supporting her reflexivity (Olmos-Vega et al., 2023).

Methods

Positive Psychology Interventions (PPIs)

The study utilised an intervention delivered through two workshops (one in person and one online) that were based on established positive psychology interventions (PPIs), and data was gathered through subsequent focus groups. PPIs have been defined as '… intentional activities that aim to cultivate positive feelings, behaviours or cogni-

tions' (Sin & Lyubomirsky, 2000, p. 468). Such techniques could include physical activity such as sport, calming interventions such as mindfulness, or thinking activities such as reflecting and reframing. All aim, however, to encourage positive emotions that increase well-being, and "promote the factors that allow individuals and communities to thrive" (Sheldon & Elliot, 1999). In the current study the workshops utilised established PPIs (see Table 1) to encourage mothers to make meaning from situations and objects ('Knowing Me, Knowing You'), reframe difficult experiences ('Duchenne Island Discs'), reflect on their strengths ('Ups and Downs of Life') and identify resources and supportive networks ('Who You Gonna Call?'), as well as take part in two mindfulness sessions. After taking part in both workshops, participants participated in a focus group to reflect on the experience of the workshops. Two focus groups, one that included two participants and one of three participants took place online. Focus groups create a space for critical reflection and the development of new insights, and have been established as an appropriate and useful way to conduct IPA research (Love et al., 2020). The topic guide utilised for the focus groups asked participants to reflect on the activities in the workshop and to consider how these activities may have supported their resilience through opportunities to reflect on their access to support and resources, to reframe challenging situations, to identify their strengths as well as to participate in short mindfulness exercises. As the focus groups were small, all participants were able to speak freely about these experiences. Although focus groups offer the chance for unstructured conversation (Cyr, 2024) the researcher was able to ensure that all participants contributed and in both focus groups participants took turns to discuss the different interventions. As such, we saw our approach as essential to facilitating a collaborative and caring research environment, aligned with a feminist ethic of care (López Radrigán et al., 2025). The research was approved by a university ethics committee.

Participants

The six participants were mothers of children living with DMD and more information about them can be seen in Table 2. Their children were aged between 8 and 15 years.

We were cognisant that IPA demands a small, purposively selected, homogeneous sample (Smith et al., 2009), but at the same time we knew that all young people with DMD and their mothers are individual. Therefore, we set the inclusion criteria for the

Table 1 Workshop activities based on positive psychology interventions

Workshop 1	Workshop 2
Knowing Me, Knowing You: introductions and sharing of meaningful objects (Martela & Steger, 2016)	Duchenne Island Discs – sharing positive emotions and savouring through music (Croom, 2012; Seligman et al., 2005; Frederickson, 2001)
Ups and Downs of Life : Identifying strengths and reframing (Seligman 2005; Padesky & Mooney, 2012)	Who You Gonna Call? - identifying resources and support from social and community networks (Lomas et al., 2014)
Guided Mindfulness exercise on Favourite Place (Brown & Ryan, 2003; Ivtzan et al., 2016)	Guided Mindfulness Exercise on a valued relationships (Brown & Ryan, 2003; Ivtzan et al., 2016)

Table 2 Participant Information (names pseudonymised)

Participant	Focus Group	Age	Age of son with DMD	Ethnicity
Elaine	1	50	8	White British
Linda	1	41	12	White British
Rebecca	1	45	12	White British
Hannah	2	39	15	White British
Lucy	2	52	13	White British

study as parents of young people between 8 and 15 years, with all young people able to weight bear. This is an important distinction in caring for someone with DMD, because as soon as a young person loses the ability to weight bear, practical caring needs increase (Strober et al., 2026). In addition, due to the need for a face-to-face workshop, we advertised for participants who lived within a 50 mile radius of the workshop venue, so that they were able to meet up in person. The small number of participants was appropriate for IPA which is interested in understanding how participants make sense of their worlds (Smith, 2004).

The charity Duchenne UK advertised the study on their social media platforms and interested mothers contacted the lead researcher for information about the study. All participants gave written consent to take part in workshops and focus groups.

Analysis of Data

The data from the focus groups was analysed using Interpretative Phenomenological Analysis (IPA). Although focus groups in IPA can risk influencing individual responses (Smith et al., 2009), it has been shown to be an appropriate method (Love et al., 2020). Furthermore, the data was analysed twice: first for group patterns, then for individual experiences (Smith, 2004). We followed Palmer's eight-step IPA process, which acknowledges researcher positionality (Love et al., 2020; Palmer et al., 2010).

Table 3 Summary of protocol for using IPA with focus group data -based on steps. Adapted from Palmer et al. (2010)

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Steps	What this involved (our summary)
Objects of Concern and Experiential Claims	Picking out key experiences and patterns
Positionality	Ensuring researcher 1 viewed data openly, and participants
Roles & Relationships	Understanding impact of relationships within focus groups
Organisations & Systems	Is there reference to systems of support?
Stories	What are the individual stories
Language	Look at metaphors and idioms, humour etc.
Adaptation of Emergent Themes	Return to 1 and link group with individual experiences – identify any conflict
Integration of Multiple Cases	Consider the 2 different groups and themes

The first author undertook the initial analyses of the focus group data, reading the transcripts closely to stay grounded in participants' accounts. Words and phrases linked to personal and structural resilience were coded, and emerging themes were developed through repeated, iterative analysis undertaken by all the authors. This was done across all transcripts to ensure themes reflected individual experiences. Three themes were identified in the data: Exploring Ways to Adapt to an Uncertain Future; How Diagnosis Makes You Stronger; and Learning to Grin and Bear It - Public and Private faces. All participants' names have been changed for publication.

Findings

Theme 1: Exploring Ways to Adapt to an Uncertain Future

The discussion in the focus groups centred on how the workshops had enabled participants to reflect on ways they have adjusted to life post diagnosis of DMD and having to accept a 'new normal'. Mothers thus acknowledged the tension between acknowledging the positive aspects of life in the moment, whilst living with uncertainty about the future. Importantly, the mothers shared how they had all made a shift from placing their hope in a cure, to living well in the moment, even though they were, "in a club we didn't ever to be in" (Linda).

Accepting the Ups and Downs

The 'Ups and Downs' activity in Workshop 1 gave participants an opportunity to reflect on their lives since diagnosis, identifying the strengths they had developed at the most challenging moments. Hannah, for example, commented:

> *... together with the mums we sort of did that graph thing with you, and I, I, did just think to myself like (*it would be good) *to show newly diagnosed mums because basically we all went down but eventually came back up, and it would just be nice. I, I loved the fact that everybody eventually came back up.*

Hannah's reflection shows how well she feels she and the other mothers have adapted to the DMD diagnosis. Her repetition of 'came back up' shows this is something important that she notices in both herself and the other parent. Whilst acknowledging that everyone's journey is individual, she notes that that they are all coping with the shared trauma of diagnosis, and that with time, the trauma would lessen. The reflection about what might be beneficial for 'newly diagnosed mums' indicates that perhaps she herself would have benefited that at the most difficult time of her life when her son was diagnosed, it would have been helpful to know that eventually she would adjust to the situation. This suggests that practitioners might seek to support newly diagnosed parents, by drawing on the experience of other mothers who have been through similar situations.

This concept of adjustment was considered in both focus groups, and participants compared ways they coped when their children were newly diagnosed with their current lives. For example, Lucy suggested that newly diagnosed families often fundraise '*to have a positive focus'* and Rebecca shared how, after diagnosis, she and her family engaged in fundraising to support medical research '*for a cure*': Rebecca commented:

> I mean, now I just don't feel that it's looking likely for E, you know, which was a bit of a blow to us, but it was nice for those few years to think, oh gene therapy's gonna come and you know it'll all be OK, that's all we just kept thinking.

This shows that for Rebecca, having hope in a cure or treatment such as gene therapy had been important when her son was younger because it enabled her and her family to keep going and feel that 'it'll all be ok'. However, her current strategies for well-being were different, for example she discussed her daily physical exercise and classes that she attended early in the morning. In contrast, for Linda, her strategy was to "benefit find" (Lechner et al., 2008), commenting that she often kept herself positive by focusing on how her family was '*better off than other people*', in terms of her standard of living and leisure activities with friends and families. Lucy discussed the importance of '*having something to look forward to'*, especially holidays.

The Tension of Living in the Moment Without Thinking About the Future

A tension did arise, however, for the mothers, in the need to live for the moment, whilst not trying to think about the future, in terms of disease progression and the consequences. Rebecca, for example, whilst perceiving herself to have moved on since the diagnosis, had devised strategies to not think about the uncertain future for her son. She stated:

> *'And he's, you know, he is happy at school. He's met S now as well. And they're getting on really well and he's still got a few friends he sees from the other school. And he's got his PlayStation and he, he's got a jigsaw…he's doing it on the table. He likes being with his dad. And, you know, he's, he's happy. So if he's happy, I'm gonna be happy. And I just think, I can't think about what's ahead. I just can't do it. I can't go there now. And I just block it. You know, that's what I've got to do because I can't. I just can't deal with it otherwise.'*

The repetition of the word 'happy' here suggests Rebecca is convincing herself to feel positive about her son's life as she focuses on the immediate present and the things her son enjoys. Mothers thus occupy a complex position, drawing on resilience skills, recognising the need to enjoy the present, whilst managing fears and anxieties about caring for a child with a deteriorative and life-shortening condition. Rebecca continued further and stated:

> And I suppose it's the unknown again, isn't it, you know? The wheelchair was that big scary thing for me, going from the buggy to that, and then now we've

> got the wheelchair, I wish we'd have got it the year before cause it was absolutely fine, you know.

Here we see Rebecca living in fear of her 'unknown' future, which in fact was not difficult but 'absolutely fine' when it happened. However, she felt the need to 'block out' the wheelchair until she was forced to face it. Similarly, Linda discussed her strategies for managing these tensions. She stated:

> I can't go too deep. Like Rebecca l, I can't think of ventilation or loss of arms. You know, it's just it's doesn't even enter my head no more. I just can't go there.

Here again we see a mother consciously deciding to live in the moment rather than plan ahead or 'go deep' to a time when her sons' health has deteriorated. Her strategy to block out the future is enabling her to live in the present.

Theme 2: Exploring How Diagnosis Makes You Stronger

Both the workshop activities and the focus groups gave mothers the opportunity to reflect on ways in which they had changed as individuals since their sons were diagnosed and they identified their new found knowledge, strengths and growing confidence in advocating for their sons, noting these strengths developed because of the lack of support from services, and by creating networks of support within the DMD community.

A Shared Strength from Diagnosis

In terms of being an advocate for their sons and the need to stay strong, Elaine, whose son was the youngest and most recently diagnosed in the group, stated:

> *I think for me it (*the workshops*) made me look at, at everyone in that group. Like people says to me all the time 'Just look at you, you're really strong, you're really this, you're really that', and I could see it in that group. I could see it with all of you. It's like you've got this sort of, like this persona, it's like, I don't know what it is, I can't describe it because I feel it as well and it's like: You are not taking us down Duchenne! You're not taking over our lives! And I could see that in everybody in the group, you know.*

This is a powerful example of the importance of creating supportive networks and being able to witness firsthand a communal strength that was apparent in mothers who have experienced life with DMD. Thus, for Elaine and the other participants, they were able to identify a complex understanding of their own strengths and resilience, moving beyond self-conceptualisation of resilience as personal feelings of wellbeing, but also growing confidence in what they all termed the ongoing "fight" for support and ensuring their son received the best care. This growing confidence gave participants the ability to deal with other aspects of the condition that might be perceived as more challenging or anxiety-provoking.

Fighting for Support and Being Viewed as 'mad'

All the participants used the word 'fight' when discussing the care for their children. Further, several talked about how they were perceived as a 'mad woman' in order to get the correct support for their children. This 'madness' involved challenging the established medical hierarchy and discussing their children's care whilst on the beach.

Linda, for example, shared details of a dispute with her son's neuromuscular clinician about giving her son heart drugs. She had discovered that best practice advises heart medication by the age of ten years (Bourke et al, 2022). She stated :

> *He wouldn't give me them* (heart drugs*). He just wouldn't. He just literally*, *just would not give me anything. So*, *so I*, *I phoned Dr D* (a cardiologist at a different hospital). *He phoned me back at 9:45pm an' I'll never forget*, *he phoned me at 9:45pm at night and he said how can I help?…. We drove the following day all the way there with B*, *an' he gave B a heart scan. And within 10 min*, *well*, *after the heart scan he said 'there are your tablets'. I went home*, *got a call from Dr P (*neuro-muscular clinician*) a week later*, *and yeah he flew off the handle with me because he found out B was on heart meds*.

Linda's story illustrates her determination to get the correct treatment for her son: making contact with a cardiologist she did not know but had heard speak at a conference, then driving 150 miles to the hospital the following day to receive it, and her confidence in challenging her son's clinician, despite repercussions.

Similarly, Rebecca recounted a conversation with her clinician when she was on holiday:

> And I remember after the phone call with C (doctor), we were on holiday in Norfolk on a beach and I was like Oh my God, what's he thinking I was running down the beach trying to get a signal like, like a mad woman shouting Don't hang up! Wait!

This shows Rebecca's resolve to garner appropriate medical support for her son, and awareness of how others might perceive this behaviour in fighting for her son as "madness". It also perhaps reveals that there is no time off as an expert carer. All the participants commented on their growing confidence in knowing their sons' needs, which at times put them in conflict with a range of professionals.

Becoming More Confident as a Person

Hannah and Lucy discuss how their sons' diagnosis of DMD had forced them to change as people. Hannah reflects on her life before and after diagnosis, saying:

> *pre- T's diagnosis*, *I was a terribly weak person. I couldn't make a single decision for myself. I mean*, *….I*, *I*, *I needed D to make every single decision for me in my life and tell me what I basically could have for tea because I couldn't*

even make that decision. And it, it did really, really push me on a steep learning curve because I knew I was gonna have to fight for T. And I kind of pushed myself to places that were really outside of my comfort zone. And, you know, I hate public speaking. I still hate public speaking now, but I, I amaze myself sometimes at some of the things that I have spoken at.

This shows how much Hannah has changed as a person since her son's diagnosis and how much more confident she has become. She perceives this as being because she has to 'fight' for her son and raise awareness of his condition through events where she has to speak publically.

Similarly, Lucy compared herself now with how she parented her older children: She stated:

You know, even just going into school, I wouldn't have done that before. Now I'm just like, it just, it just comes out. So I think you're right. I think it's just, you know, you have to fight for some, for everything really, don't you? So you just do have the confidence that I suppose comes with that.

Again, Lucy states that as a mother of a child with DMD, you do not have the choice but to fight for the necessary support for your son. This suggests that despite the well known physical trajectory of DMD, and the established neuro-divergent risks, schools and services often do not give the appropriate resources to young people with DMD. However, fighting for necessary care, and raising awareness of the needs associated with DMD, was perceived by all participants to have unintended positive consequences, including increased confidence and the development of new strategies for managing all aspects of their sons' care and support.

Theme 3: Learning to Grin and Bear it - The Emotional Labour of Motherhood and DMD

Both focus groups reflected on how their sons' diagnosis had affected the ways in which they interact with others. Participants discussed the pressure to behave differently across a variety of social settings and the need to be careful about how they shared information with people who lacked understanding of the condition. This felt like a heavy responsibility for mothers.

'Quick, there she is! Hide! ' - Speaking about Duchenne to Other People

Rebecca discussed why she was late to the online workshop and the challenge of talking about DMD, even with people in a similar situation. She commented:

…so then when I came to join you…. I was all a bit dishevelled 'cause I hadn't really been thinking about Duchenne at all and, so I think so, I think when I meet the other mums, and I know that we're gonna talk about Duchenne and I'm sort of not mentally prepared for it.

As Rebecca finds it difficult to talk to other mums with DMD when ' I know we're going to talk about Duchenne' suggesting that in her day-to-day life it is easier not to think about it. She implies that she may have felt differently if she was 'mentally prepared for it' suggesting that she is able to build her resilience to face issues related to DMD when she needs to. However, this 'mental preparation' is not always possible, when people who do not understand DMD ask about her son. She says:

> .a lot of people say ohh, how's E? And then I think, well, if I really told you what's really happening, you know then they would be really shook up. That is what people say to me sometimes so, so will his arms not work anymore? and will this and that? And I'm like yeah, it's a muscle his heart, it's the biggest muscle and they just like go 'oh my God', and I don't know what to say.

Here Rebecca implies that she often feels obliged to prioritise other people's distress over her own, stating *'I don't know what to say*' even though she is very aware of her son's deterioration and would be able to articulate well if necessary. She reflects that possibly people would avoid her if she told them the truth saying:

> You don't want to come across as a big depressive, do you?…Quick! There is she is, hide!

This was experienced by other participants in the groups, namely the need to suppress their feelings, to protect other people's discomfort and distress at the reality of their son's disability.

Feeling Alone

Hannah, who is very active on social media, shared how she has been unable to share any information about her son's recent mental health crisis with people, including close family members:

> *they just wouldn't be able to cope with it. That's why sometimes I think I box myself off because I can't tell people all that stuff. Can't tell my mum that 'cause she'd just freak out completely.*

Again, this suggests Hannah has to privilege other people's emotions over her own to protect them, even though she and her son were dealing with very challenging circumstances. She says she has to 'box herself off' implying that she has nobody to share these difficult feelings with. Similarly, Lucy did not volunteer information about her son to people who were not affected by DMD, stating:

> When I go out, I don't, like, say I don't really want to talk about it, or, realistically, no one really wants to listen either.

Again, Lucy has to keep her feelings to herself because she feels that there is nobody to listen to her worries about her son. Not talking about DMD, therefore, appears to have

emerged as a strategy with negative implications for the mothers. Despite how important such conversations could be in helping counteract the feelings of being alone, children living with life-shortening conditions, with disabilities, remain a taboo subject for many people, including professionals, leaving such conversations unspoken.

Discussion

The findings from this study suggest that the use of positive psychology interventions (PPIs) can enable mothers of children with DMD to identify and acknowledge personal resilience, despite a lack of systemic support or indeed in the face of systemic challenges. Research in other health areas, such as cancer, has noted that as a serious diagnosis is often viewed as threatening and random, being able to identify growth can help to restore a sense that life can be fair and meaningful and thus foster adjustment to a diagnosis (Park & Peterson, 2008; Holland & Reznik, 2005). Furthermore, it has been suggested that resilience has three possible trajectories that include bounce-back, sustained well-being or post-traumatic growth (PTG) (Joyce et al., 2018, p.294), with the latter referring to a situation in which a person functions better than they did before the adversity occurred (Tedeschi & Calhoun, 2004). People who manage to adjust their views are more likely to experience PTG, whereas those who hold onto their original world outlook and try to assimilate this with their post- trauma situation will struggle to cope (Joseph & Linley, 2005). The workshops and focus groups enabled the mothers to identify aspects of PTG, such as an improved ability to advocate both for themselves and their child, and an increased confidence in decision-making and problem-solving. By taking part in activities based on established PPIs, mothers explored and acknowledged the resilience they had developed in the light of their sons' life-changing diagnosis. This opportunity to reflect gave mothers the chance to reframe difficult times and learn from each other.

However, growth had not been linear, and even those who appeared to find adjustment difficult have developed a variety of new skills, and those who acknowledge growth still struggle to adjust to some challenges.

This uneven adjustment is particularly important when considering the deteriorative nature of DMD. A 'fear of the future' has been well documented as a prevalent issue for parents (Thomas et al., 2014; Porteous et al., 2021). Porteous and colleagues (2021) note that stress and worry for parents' peak at predictable 'life changing moments', or milestones in the course of DMD, such as loss of ambulation, using a ventilator or losing a peer to DMD. However, interestingly, in this study, participants shared that it was the fear of these 'life-changing moments' rather than the moments themselves that caused them the most emotional difficulties. Indeed, Rebecca reported that despite the wheelchair being 'a big scary thing' before her son needed it, it was in fact 'absolutely fine' once he was using it. This could suggest that an unnecessary fear of the future can reduce the quality of life for families in the present, as they dread unknown and future stages of the condition. However, it is also true that not focusing on the future can be a useful strategy for mothers to enable them to focus on the present and live in the moment. It is therefore important for professionals to understand that it is possible to hold both positions simultaneously and that fear of the future should not preclude discussing plans for future life.

Furthermore, mothers reported consciously masking their emotions to cope with their fears and grief. This often included privileging the feelings of others over their own when talking about DMD, or the challenges it brings. This resonates with findings from research with mothers of children with learning disabilities. Runswick-Cole (2013) uses the term 'emotional labour' to describe the emotional rather than the physical work that mothers of disabled children are forced to undertake as they are often forced to 'wear it all with a smile' (p6).

Finally, the intervention, and indeed the focus group discussion, offered mothers the opportunity to identify the attitudes and systems that can test and challenge their resilience, making it difficult for them to access the resources they need. In research on parenting disabled children, Ryan (2005) notes that mothers begin as 'worriers' and end up as 'warriors', while others describe how mothers are forced to become 'vigilantes' (Blum, 2007, p. 205). This is apparent in this study where Linda tracked down a cardiologist herself, to obtain necessary medication for her child, and when Lucy had to keep fighting with school, despite the recognised learning differences established in DMD. This aligns with a recent study with mothers of adults with learning disabilities, which found that services can sometimes be seen as 'gaslighting' mothers by ostensibly offering them support that they qualify for, yet at the same time making it difficult to attain this support, inferring that mothers are 'mad' to expect it (Runswick-Cole et al.,., 2024).

Implications for Practice

Ensuring that mothers of young people with DMD feel supported, is an important role for both health and social care teams. Practical and psychological challenges abound for these families, and it is essential that professionals acknowledge the expertise of mothers' lived experience and listen to their concerns. A strengths-based approach should be utilised to support families in understanding how well they are coping, rather than focusing solely on disease deterioration and carer burden (Peay et al., 2016). Parental anxiety during an appointment might be a normal reaction to living with a deteriorative condition, and not necessarily something to be pathologized. Some mothers, however may benefit from extra support such as therapy or counselling, and there should be a clear pathway for accessing this resource using a stepped care approach (NICE, 2009). It is essential that all health and social care teams believe a good life with DMD is possible, and offer people with DMD and their families holistic care that focuses on 'human aspects of care' rather than physical decline exclusively (Setchell et al., 2018; Morrow, 2004). Indeed, we would argue that the pilot intervention, could potentially be an effective approach to support not only mothers, but family members caring for a young person with a range of life shortening conditions.

Teams should consider how best to normalise key transitions in a timely way so that families can enjoy life in the moment and plan for the future. This might include signposting families to parent-led support groups to help them network with other families. Furthermore, facilitating meetings between families of older children and those who have younger children could enable families to better accept the wheel-

chair or ventilator rather than fear them. It could help normalise key 'life changing moments' that families fear, especially as it is acknowledged that building resilience is best supported early (Ungar, 2011).

Limitations

There are several limitations of this study. Firstly, this small group of mothers is not representative of all mothers of children with DMD, and those who self-referred may be coping better with the diagnosis than those who did not. Furthermore, all participants' sons were either still walking or able to weight-bear, and conversations with mothers of older children with DMD may well have highlighted more practical challenges such as the physical nature of care and support, obtaining employment, and relationships (Yamaguchi et al., 2019; Strober et al., 2026). The intervention was a pilot, and therefore future interventions should be more robustly evaluated, use pre and post-test validated scales, with longer term follow up.

Conclusion

This is the first published study in DMD that we are aware of to offer Positive Psychology Interventions (PPIs) to mothers. It is also one of very few articles using a qualitative design to collect rich data about the lives of mothers with DMD. Despite the emotional toll of fighting for services, fearing the future and feeling isolated, mothers were able to reframe these experiences in workshops and focus groups, acknowledging both individual and shared strength within the group. We would therefore advocate that health and care teams employ a dialectical approach to support mothers of children with DMD. This involves acknowledging the moments of anxiety, grief and loneliness without pathologising mothers, whilst at the same time offering opportunities to notice strengths, growth and knowledge. Working in partnership with parents is more effective than working against them, and teams should appreciate the expertise of lived experience that mothers can offer in such a rare condition. This small-scale pilot study suggests scope and value for developing workshops that incorporate positive psychology interventions (PPIs) further, not only for mothers of young people with DMD but for carers of children with other health conditions. Further research could evaluate their effectiveness by measuring changes in parental well-being and self-determination before and after participation. Finally, these findings suggest that consideration must be given to how to best prepare families of young people with DMD for the future in a timely way so that the present is not negatively affected.

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Declarations

Ethical approval The research has been approved by a University Research Ethics Committee. We certify that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Clinical trial number not applicable.

Informed consent All participants gave informed consent to take part in the research. The research has been approved by a University Research Ethics Committee.

Competing interests The authors declare no competing interests.

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