

# Sexual health and fertility in Duchenne muscular dystrophy—An exploratory study

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## Abstract

**Introduction/Aims:** Recent clinical guidelines recommend that adolescents with Duchenne muscular dystrophy (DMD) who are on daily glucocorticoid treatment should be offered pubertal induction in order to ensure adult levels of sex hormones as they reach adulthood. However, it remains unclear how gonadal status, including androgen concentrations, impacts physical function and future fertility. The aim of this study was to give a voice to adults with DMD, exploring their perspectives around sexual health, hormone treatment, and fertility.

**Methods:** Qualitative data was collected from six adults with DMD through two online focus groups. Participants were recruited through Pathfinders Neuromuscular Alliance and Duchenne UK and invited to take part if they had DMD and were 18 years of age or older. Conversations were transcribed verbatim and an interpretivist paradigm was used with thematic analysis.

**Results:** The main themes identified were (1) the need for communication and information about sexual health, (2) dealing with the potential fear of rejection, (3) physical barriers to relationships including sex, (4) testosterone supplementation in DMD, and (5) parenthood and fertility.

**Discussion:** We recommend that clinicians work with young people with DMD individually, to explore the benefits of testosterone treatment for them and their personal sexual health needs. If they are offered treatment, this should always be accompanied by the opportunity for psychological support. This work highlights the need for further research to establish the role of testosterone supplementation in adults with DMD and its effects on fertility and the value of specific emotional and practical support for sexual health.

## KEYWORDS

disability, Duchenne muscular dystrophy, fertility, psychosocial, sexuality, testosterone

**Abbreviations:** DMD, Duchenne muscular dystrophy.

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## 1 | INTRODUCTION

Improved treatment options and supportive care such as cardiac management and non-invasive ventilation mean that adults with Duchenne muscular dystrophy (DMD) are living longer, with some individuals surviving into their third and fourth decades.<sup>1,2</sup> Delayed puberty is almost universal in those on daily glucocorticoid treatment and induction of puberty has been included in the revised DMD standards of care, so that adolescents with DMD should increasingly be transitioning with adult testosterone levels. Benefits of this include increased bone mineral density, red blood cell production, lean muscle mass, and self-esteem. Notwithstanding their physical limitations, most adults with DMD perceive a good quality of life,<sup>3</sup> and interviews with adolescents with DMD who were undergoing pubertal induction indicated that the majority want to be treated the same as their peers without disabilities.<sup>4</sup> Despite calls for a bio-psycho-social model of DMD that would offer holistic support for the young person and their family,<sup>5</sup> research and care for this condition remain firmly embedded in a medical model of disability, and little acknowledgment is given to psychosocial needs.<sup>6</sup> This means that as young people with DMD transition to adulthood, there is often a lack of discussion around wider issues including sexual function and the desire to form more intimate relationships,<sup>7-9</sup> despite these being key concerns reported by “unanticipated” adults.<sup>10</sup> Furthermore, in addition to multiple levels of discrimination, people with disabilities, including those with DMD, are often portrayed as a homogenous group that is both gender-less and sex-less.<sup>11</sup> It is not surprising, therefore, that there has been an absence of conversations around intimate relationships in research interviews with adults with DMD, and discomfort when this topic is raised.<sup>12</sup> More recently, in recognition of the pubertal process being vital for emotional and physical well-being,<sup>4</sup> prompt induction of puberty has been included in the revised DMD standards of care,<sup>13</sup> so adolescents with DMD should increasingly be transitioning with adult testosterone levels. It remains unclear how individuals with DMD feel about this and how gonadal status, including androgen concentrations, impacts on physical function and future fertility. There is a pressing need to understand how young people and adults with DMD perceive their sexual health. This small pilot study explored the ideas, concerns, and expectations of adults with DMD regarding sexuality and disability as well as their thoughts about fertility.

## 2 | METHODS

Two online focus groups were held to explore the themes surrounding sexual health and fertility. Ethical approval was obtained from the Newcastle University ethics board (02146) and participants were recruited through the social media platforms of Pathfinders Neuromuscular Alliance and Duchenne UK. Each online focus group took around one and a half hours. Both groups were video recorded through Microsoft Teams, and the conversations were transcribed verbatim. All participants had a diagnosis of DMD and were 18 years of age or older. They were given a patient information leaflet prior to

the focus group. All gave written consent to take part in the research. Two authors (JH and CW) moderated the online session.

This study used an interpretivist paradigm.<sup>14</sup> Interpretivism is an approach that views truth and knowledge as subjective, based on people's experiences and how they understand them. This is in contrast to positivism which views reality as the same for every person.<sup>15</sup> For this study, an interpretivist approach was deemed most appropriate as the aim was to understand how men with DMD made sense of their experiences with sexuality and testosterone supplementation, either for induction of puberty or to support low androgen levels in adulthood. Therefore, knowledge was socially constructed through two online focus groups in which participants discussed these issues. The use of two smaller focus groups (with three participants each) was deemed appropriate to enable free-flowing conversation and to facilitate the sharing of personal issues.<sup>16</sup> To ensure good quality conversations around challenging topics, we followed the advice of Jepson and colleagues, allowing pauses and spaces for participants to talk, and forewarning of anything that might be considered very sensitive or taboo.<sup>17</sup>

Data were analyzed using thematic analysis.<sup>18</sup> Thematic analysis is used in qualitative research to rigorously identify, analyze, and make sense of patterns of meaning across a dataset, and has been established as an appropriate method in healthcare research.<sup>19,20</sup> Braun and Clarke's six-step approach was utilized, and through an iterative process, the two lead researchers (JH and CW) individually familiarized themselves with the transcripts once they were typed and checked, before meeting to agree on initial codes.<sup>18</sup> Next, they identified and shared quotes that related to overall themes. These were distributed to the other authors for their opinions and approval before reviewing and naming the final themes. To protect anonymity, participant names were replaced by numerical codes.

## 3 | RESULTS

Data were obtained from two online focus groups, each including three participants. See Table 1 for details. Eight young adults (all of whom identified as and were natal men) responded to the initial advertisement and of these, six were able to attend one of the two planned focus groups. The six men were aged 24–48 years. Five main themes were identified during the thematic analysis and are presented in the next section along with subthemes in Tables 2–6. Five of the six participants had been treated at some point with glucocorticoids; one only as part of the requirements for a clinical trial when he was a teenager, whereas the remaining four were still on a steroid regimen. One participant had never been prescribed steroids.

### 3.1 | The need for communication and information about sexual health (Theme 1)

Communication was a key theme that featured throughout both focus groups. All participants highlighted the value that they placed on having confidantes and of being spoken to like an adult and “not

Participant	Age (years)	Steroid use	Testosterone use
1	24	Yes	Yes
2	33	Yes	No
3	25	Briefly, as a teenager only	No
4	48	No	No
5	24	Yes	No
6	24	Yes	No

TABLE 1 Participant characteristics.

TABLE 2 Example quotes from Theme 1: The need for communication and information about sexual health.

### Theme 1: The need for communication and information about sexual health

#### Subtheme 1.1: Finding the right person to talk to

"It would have been really helpful when I was a teenager" (to have someone to talk to)  
 "It's very difficult to find people to talk to and I haven't got that many friends really" (Participant 4)  
 "Some people might prefer their mum and dad. I think I would probably have preferred someone I didn't know because I feel like I would be able to open up a bit more, ask questions more so than with my parents." (Participant 4)  
 (My friends with disabilities can be) "very open about their experience" (Participant 4)  
 "A consultant isn't going to be able to give you that space because of time pressure" (Participant 1)  
 "I would not want to talk to my consultant about this despite having a good relationship" (Participant 3)  
 "It would be really helpful if a clinician could just talk to parents, to say there's something you should talk about openly" (Participant 5)

#### Subtheme 1.2: Information about facilitating sex with a disability

"There isn't really anywhere that I can think of where you can go and get the support that you need personally that is adapted to your needs." (Participant 3)  
 "There's nothing really bespoke for people with our condition, and I guess the best kinds of information I've had is talking to other people who have been in similar situations." (Participant 4)  
 (regarding masturbation) "So we are coming up with solutions and they're not being shared;" (Participant 4)

#### Subtheme 1.3: The right to have sexual intercourse

"Research has proven how it can make someone happier and more positive about their life or themselves, confidence and all that." (Participant 2).

#### Subtheme 1.4: Assumptions of heterosexuality

"There's a definite lack of information in terms of sex for disabled gay men in particular" (Participant 4)

patronized." This opportunity was not available to the participants while they were growing up, and all felt it was missing from their care. All spoke of the importance of their families, but several recognized the need to be able to talk to someone different about sensitive subjects like sex and relationships. There were differing opinions regarding who was best placed to support these conversations, but it was acknowledged that it takes time to build up trust and that the conversations are not easy ones to have. Those that had friends with disabilities valued being able to talk to them, but others who had attended

TABLE 3 Example quotes from Theme 2: Dealing with fear of rejection.

### Theme 2: Dealing with fear of rejection

#### Subtheme 2.1 Self-esteem and confidence

"...It's a hard slog and it's quite mentally draining to do it and to keep putting yourself out there all the time knowing that most likely it's going to be a rejection." (Participant 4)

#### Subtheme 2.2 Feeling different

"I don't ever show my wheelchair in dating app photos" (Participant 2)  
 "Once you start using a ventilator, I think, it's become much harder" (Participant 4)  
 "People's perceptions or how you think they might respond because of the chair and things like that and also I think then that makes you dismiss yourself sometimes." (Participant 3)

#### Subtheme 2.3: Coping with rejection

(There is a need for) "Ongoing support to deal with rejections" (which should be in the form of) "workshops where we can talk to peers." (Participant 4)  
 "It's deciding that it makes you stronger; so it shapes me as a person that I am today. Those experiences make you feel more normal, and it makes you feel more like you can relate to other people and if they talk about it then you can also talk about it." (Participant 5)

mainstream schools did not tend to know other young people with disabilities well enough for discussion of these issues. Several participants spoke about how helpful it was that they could speak to their personal assistants, and all agreed that having a "dedicated person" to talk to about sexual health would be the preferred option. Three participants agreed that this should not be their neuromuscular clinician. Conversely, others from racially and culturally minoritized groups felt strongly that the clinicians' role could be to encourage parents to have these important conversations seeing as this was not something their parents would do naturally, suggesting that if the clinicians recommended it then parents would follow their advice and enable these important discussions.

In addition to a lack of communication on the subject, participants reported how difficult it was to find any information about sexual health. One participant found watching documentaries about sex for people with disabilities helpful, but most voiced a lack of places to go for help, explaining that if advice was available, it tended to treat people with disabilities as a homogeneous group rather than meeting individual needs. One participant added that some subjects such as masturbation are not discussed in the DMD community, leaving people to find individual solutions alone. Another participant reported a dearth of information and advice for gay men with disabilities and felt

**TABLE 4** Example quotes from Theme 3: Physical barriers to sex and relationships.**Theme 3: Physical barriers to sex and relationships****Subtheme 3.1: Lack of inclusive spaces:**

(the biggest issue is) "Access to buildings and stuff" (Participant 3)  
 "The issues that I'm having now is that, because I can't project my voice loud enough, it's hard for me to communicate with anyone that I want to talk to. So unless there's a very quiet room then it's really difficult for me to have that interaction" (Participant 2)  
 "One thing as well that's quite annoying is the access, for example, to dating sites, a lot of them aren't accessible properly, like on different platforms but you have to use your phone." (Participant 5)

**Subtheme 3.2: Using paid services**

"I try and do it, it's a lot of organizing as you can imagine." (Participant 2)  
 "My parents don't know, actually they don't know about any of it. I probably would like to tell them about it, and actually that would lift a lot of weight off my shoulders if I could openly talk to them about it and also means I would be able to get it a bit more regular...It's good, but I've realized I want a relationship and it's not always about the sex, it's just about having someone to share experiences with. Anyway, sometimes with the escorts I just sit and talk to them. Like we just sit and hug and I just talk to them, sometimes it can be like that." (Participant 5)  
 It would be "a weight off my shoulders" (telling my parents about using escorts) (Participant 5)

**TABLE 5** Example quotes from Theme 4: Testosterone and fertility treatment.**Theme 4: Testosterone and fertility treatment****Subtheme 4.1: The right to testosterone treatment**

"Although it's very difficult wanting relationships and dealing with a lot of rejection, I think I would much rather have that than be stuck in a pre-pubescent state basically." (Participant 4)  
 "As a young man going through puberty relatively later, I felt psychologically I struggled with that and yeh I did have issues, I guess the kind of usual teenager anxiety about that really." (Participant 1)

**Subtheme 4.2: Lack of psycho-social support for testosterone treatment**

"It's like we'll give you this testosterone because we know it might help you, but the support around that as far as I know hasn't been there. It's like try this and see how we get on, just let us know if that's anything major happening." (Participant 3)  
 "I think it is more linked to mental health because it brings out all these emotions and feelings and obviously maybe 10/15 years ago it wasn't really a priority...so I think support needs to match that, that drive people are having." (Participant 2)

frustrated that if sex is discussed at all it assumes heterosexuality. This suggests that lack of communication and information around sexual health is forcing adults with DMD to locate their own resources and specialist help and expertise.

**3.2 | Dealing with a fear of rejection (Theme 2)**

Throughout the discussions in both focus groups, views about sex and relationships appeared to be closely linked to participants' fears of

**TABLE 6** Example quotes from Theme 5: Fertility and parenthood.**Theme 5: Fertility and parenthood****Subtheme 5.1: Impact on own life and life of child**

"Realistically by the time your child is 15 or 20 you're not going to be there" and "I think about how long you're going to be around for and the pressures... problems that that can cause." (Participant 1)  
 "I'm not sure it'd be fair." (Participant 6)  
 "You've got to try and manage your condition and your child." (Participant 1)

**Subtheme 5.2: Significance of having an inherited condition**

"I think I'd be quite worried and scared that if I had a child with Duchenne, I know what they'll have to go through." (Participant 2)

**Subtheme 5.3: The importance of legacy**

"It's definitely something that's been on my mind, and I think it would be quite nice to be able to do." "Obviously finding the right relationship and partner I think is key." (Participant 3).  
 "A lot of people think about it in terms of a legacy" suggesting that "people were lying if they said they hadn't." (Participant 5)  
 "It's a selfish reason for wanting kids." (Participant 1)  
 "There's definitely more conversations to have around that. We know of people who have done it, so it's possible." (Participant 3)

rejection and lack of confidence. Both groups shared how this fear often stopped them from pursuing a relationship. Furthermore, participants discussed the pressure of societal and ableist notions of sexual attraction. For example, several talked about people's views about the wheelchair and the ventilator, with one person noting how they never showed their wheelchair in photographs on dating apps. Others discussed how normative assumptions about disability created a key barrier in finding a partner, sometimes causing them to internalize the discrimination they experienced.

Participants shared different ways this could best be supported. One participant suggested that workshops to support people to deal with rejection would be helpful. However, other participants suggested that rejection played an important positive role in "making you strong" and helping you to feel "more normal" as you can talk to people without disabilities about it. Therefore, while it was unanimously agreed that rejection is part of the journey for people with DMD, participants wanted help to be given on how to best deal with this. Linked to the psychological challenges associated with sex and relationships are barriers caused by practical challenges and access; these are discussed in Theme 3.

**3.3 | Physical barriers to sex and relationships (Theme 3)**

As well as psychological barriers, participants spoke about the practical difficulties in meeting people due to a general lack of disabled access to some public buildings such as pubs and nightclubs. Others reported that "even if they could get inside," the music was often loud, and some found it difficult to hear over the sound of their ventilator which could make conversation impossible. In addition to physical access to buildings, virtual spaces were often deemed inaccessible.

The need to swipe on people's profiles on online dating apps meant that people with limited hand movement could lose the chance to connect with someone they wanted to get to know. Participants agreed on the positive impact on well-being of being able to have sexual intercourse, but noted the practical barriers preventing them from achieving this. The need for personal assistants to help with practical issues such as sexual positioning could cause challenges and participants reported that not all personal assistants in the care team would be prepared to help with this. One practical solution to these challenges for two of the participants was meeting paid escorts. It was acknowledged that this was a taboo subject that had legal implications, and not something that participants felt they could talk openly about with family. Indeed, one participant shared his anxiety about hiding his escort experiences from his parents, reporting that it would be a great relief if he could tell them. However, despite these positive sexual experiences, participants acknowledged a desire for close relationships rather than just sexual ones and the importance of having an intimate and meaningful relationship.

### 3.4 | Testosterone supplementation in DMD (Theme 4)

Participants also felt that communication and information around testosterone supplementation should be consistently offered. The participants were very much in favor of being offered induction of puberty or supplementation of puberty if needed. It was agreed that the psychological support provided could be improved so that it is individualized rather than leaving patients to experience it alone.

### 3.5 | Parenthood and fertility (Theme 5)

When the discussions moved to parenthood, there were mixed feelings from the participants regarding starting a family, but all acknowledged that they had given the matter thought. Three participants questioned their ability to be competent parents when dealing with a deteriorating condition themselves, as well as worrying that they might not live long enough to care effectively for their child. Some expressed fear that they might have a child with DMD, indicating the need for education around genetics and DMD. As the dystrophin gene is on the X chromosome, a male born to a man with DMD would not inherit DMD, whereas any daughter would be an obligate carrier. In contrast, some participants were positive about having children, reporting that they knew of others who were parenting successfully and felt it would give them a legacy.

## 4 | DISCUSSION

Our findings echo earlier studies reporting that sexual health and relationships are a very important and often neglected factor in the lives of adults with DMD.<sup>7,10,17,21</sup> The need to talk about these issues in a

nonpatronizing way was overwhelmingly agreed upon as essential, although participants were divided about which individual or team is best placed to do this. Some felt that their neuromuscular clinician should be talking to them about this, whereas others preferred to speak to friends with disabilities if they had them. Many spoke about not wanting to speak to their parents. Notwithstanding these differences of opinion, it was clear that taboos surrounding sex and relationships and disability need to be challenged in order to improve both the physical and mental health of adults with DMD, and this could possibly be achieved by normalizing conversations in early teens about sexual health with the young person and their family. An opportune time for introducing these discussions and highlighting their importance may be during the transition process from a pediatric to adult neurologist, particularly as adult clinicians may be more comfortable and have greater experience discussing these potentially sensitive issues. For adults with DMD in England who may be using Personalized Health Budgets and Direct Payments, the neuromuscular clinician might be the only consistent professional in their lives. The idea that sexuality is not based only on physical performance but is closely connected with emotional closeness and pleasure was reiterated by several of the participants. This is particularly important since it has been established that once they have completed their education, many adults with DMD can become socially isolated with little opportunity to speak to other people.<sup>6</sup> For this reason, Abbott et al. suggest that social care staff should initiate conversations about “sensitive topics” such as sex and gender, but in many cases where care is provided through direct payments in the UK and where adults with DMD are the employer this becomes more complex.<sup>7</sup>

The complexities involved in employing people to support intimate aspects of care have been noted by many, and this can be exacerbated for both the person with disabilities and their carer if it is not discussed properly beforehand and boundaries agreed.<sup>22</sup> Adults with DMD must have appropriate support available to them when facing these challenges, and in a wider sense, to have somebody with the appropriate expertise to discuss their sexual well-being. The men in these focus groups commonly spoke of the importance of this person being someone with “time.” Furthermore, participants suggested that the lack of appropriate information relating to having sexual intercourse, and how this could be facilitated, is problematic. As has been noted by others, some adults with DMD in the UK and across Europe benefit from meeting sex workers, and some participants in this study valued this opportunity.<sup>7,23</sup> However, the logistics of support and positioning means that personal assistants need to be willing to help, and the implications of this can be challenging. The issue of sex workers and adults with disabilities is not new, and this is clearly a challenging area to navigate, in order to facilitate the concept that sexual expression is a fundamental right of every individual.<sup>24</sup>

All participants reported on the impact of ableism which privileges the needs and experiences of people without disabilities, and which affects the ways in which people with disabilities view themselves, particularly as sexually active individuals.<sup>25</sup> Participants agreed that this affected the ways in which they presented themselves on social media and dating sites, and both groups spoke at length about their



fears of rejection. On the other hand, it was interesting to note that at least two participants felt that rejection was a positive experience as it made them “more normal”, indicating the need for resilience building around this area. To quote from Abbott et al.<sup>7</sup> “The ability of men in the study to sometimes redefine and reshape themselves in the face of an ableist society and sometimes impoverished forms and amounts of support from the State speaks to their tenacity and resource.” Research in the general population suggests that offering support to develop resilience before difficult events occur is more effective than after the challenges have occurred.<sup>26</sup> This therefore might be achieved through regular psychosocial support and the chance to discuss relationships through teenage years.

As all participants had considered parenting, this issue should be discussed with them at clinic at the appropriate stage. It should not be assumed that because they have a disabling and life-limiting condition that they will not want to be parents. There are very little data available, but it is suggested that the image of parenting as a person with disabilities held by society is dominated by negative aspects such as practical difficulties, lack of abilities and not fulfilling one's role properly.<sup>27,28</sup> This may partly result from inadequate knowledge about these parents' experience, special and everyday needs, and about the significance of support. One participant reflected on his life-limiting condition and the challenge of looking toward an uncertain future when considering parenthood. It is likely that the attitudes of these young adults may change in parallel to their physical functionality, a concept that has been described previously.<sup>8</sup> On the other hand, several participants spoke about how having a child was something they had considered from an early age if they found the right partner, and how this might serve as their legacy.

The views expressed in the focus groups were limited by the 6 young adults who responded to the advertisement all identifying as men. Furthermore, as the study had been advertised as an opportunity to discuss sexual health and function only participants keen to discuss these issues chose to participate and therefore many perspectives will not be represented. In addition, the limited focus of the study meant that caregivers, aides, physicians, and other members of the multidisciplinary team were not invited to participate.

## 5 | CONCLUSION

It is important to recognize that as in any other sector of the population, the DMD community is not a homogenous group and that people's perspectives will vary according to their own background and culture. As more adults with DMD are living longer and direct their own care, the members of the clinical team are often the only consistent professionals with whom they are involved. This highlights the importance of talking to young people about their sexual as well as relationship needs, as there may be nobody else with whom they can do this.

We recommend, therefore, that clinicians work with young people with DMD individually, to explore the benefits of testosterone treatment for them and their personal sexual health needs. If they are offered treatment, this should always be accompanied by the

opportunity for psychological support. This work highlights the need for further research to establish the role of testosterone supplementation in adulthood and its effects on fertility. The study also demonstrates the need for specific emotional and practical support for sexual health in adults with DMD.

## AUTHOR CONTRIBUTIONS

**Janet Hoskin:** Conceptualization; methodology; investigation; writing – original draft; writing – review and editing; formal analysis; project administration; validation; data curation. **Timothy D Cheetham:** Conceptualization; investigation; writing – original draft; writing – review and editing. **Rod T Mitchell:** Conceptualization; investigation; writing – original draft; writing – review and editing. **Sze Choong Wong:** Conceptualization; writing – review and editing; validation. **Claire L Wood:** Conceptualization; investigation; writing – original draft; methodology; validation; writing – review and editing; formal analysis; project administration; data curation.

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## CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

## ETHICS STATEMENT

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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