Disabled men with muscular dystrophy negotiate gender

David Abbott, John Carpenter, Barbara E. Gibson, Jon Hastie, Marcus Jepson & Brett Smith

To cite this article: David Abbott, John Carpenter, Barbara E. Gibson, Jon Hastie, Marcus Jepson & Brett Smith (2019): Disabled men with muscular dystrophy negotiate gender, Disability & Society, DOI: 10.1080/09687599.2019.1584093

To link to this article: https://doi.org/10.1080/09687599.2019.1584093

© 2019 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

Published online: 18 Mar 2019.

Submit your article to this journal

Article views: 24

View Crossmark data
Disabled men with muscular dystrophy negotiate gender

David Abbott\textsuperscript{a}, John Carpenter\textsuperscript{a}, Barbara E. Gibson\textsuperscript{b}, Jon Hastie\textsuperscript{c}, Marcus Jepson\textsuperscript{d} and Brett Smith\textsuperscript{e}

\textsuperscript{a}University of Bristol, Bristol, UK; \textsuperscript{b}University of Toronto, Toronto, ON, Canada; \textsuperscript{c}DMD Pathfinders, Shoreham-by-Sea, UK; \textsuperscript{d}University of Bristol, Bristol, UK; \textsuperscript{e}University of Birmingham, Birmingham, UK

**ABSTRACT**

Disability is often portrayed as a one-dimensional category devoid of further intersections. Work which has addressed the intersection of disability and male gender has rarely considered different types of disability or impairment, or foregrounded the experiences of disabled men themselves. This article is based on empirical work carried out in England with men who have Duchenne muscular dystrophy (DMD). We explored with participants their sense of themselves as men and their commonalities and differences with other men. Findings suggest that men with DMD claim, reject and redefine what it meant to them to be men. Doing gender was often heavily reliant on the availability and permission of others. Our study highlights the usefulness of exploring gender with men with particular experiences of disability and of looking at how this might change over a life course, especially when the nature and extent of the life course is a precarious one.

**ARTICLE HISTORY**

Received 27 September 2018
Accepted 14 February 2019

**KEYWORDS**

gender; Duchenne muscular dystrophy; intersectionality; life course

**ABSTRACT**

Disability is often portrayed as a one-dimensional category devoid of further intersections. Work which has addressed the intersection of disability and male gender has rarely considered different types of disability or impairment, or foregrounded the experiences of disabled men themselves. This article is based on empirical work carried out in England with men who have Duchenne muscular dystrophy (DMD). We explored with participants their sense of themselves as men and their commonalities and differences with other men. Findings suggest that men with DMD claim, reject and redefine what it meant to them to be men. Doing gender was often heavily reliant on the availability and permission of others. Our study highlights the usefulness of exploring gender with men with particular experiences of disability and of looking at how this might change over a life course, especially when the nature and extent of the life course is a precarious one.

**Points of interest**

- Disabled people are often treated as one group and other important aspects of their identities are ignored.
- Gender is often overlooked by non-disabled people as a crucial part of identity, for example what might matter to disabled men or disabled women.
- This article talks to disabled men who have Duchenne muscular dystrophy about how they think about themselves as men – and how other people may or may not pay attention to this.
- The men in our study talked about how their experience of living with Duchenne muscular dystrophy shaped their gender identity in both positive and challenging ways.

**CONTACT**

David Abbott d.abbott@bristol.ac.uk

© 2019 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group. This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (http://creativecommons.org/licenses/by-nc-nd/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.
Introduction

Disabled men and women continue to face multiple layers of discrimination and oppression (Eide and Ingstad 2017; Heslop and Emerson 2017; Morris 2011). Just one consequence of this has been the characterisation of disability as a sometimes homogeneous category. Thus, society portrays the gender-less, sex-less, race-less disabled person. For many disabled people, the disability label foregrounds all others. The central problem with this is not the label itself, as many disabled people claim and celebrate the label as much as other labelled groups in society (Shakespeare 1996). The issue is that the singular labelling is normally the work of non-disabled people operating on a set of ableist assumptions. The extreme ‘othering’ of disabled people by non-disabled people in society means that other identities for disabled people are unimaginable. Commonalities of gender, race, sexuality or class, for example, are lost and inconceivable. As Charmaz suggests:

Visible disability typically becomes a master status and a master identity. It is a master status because this position overrides and subsumes others; it is a master identity because it defines every other identity. (1994, 277)

Challenges to the invisibility of gender in the political disability community have come primarily from disabled, feminist writers (Crow 1996; Morris 1993; Zitzelsberger 2005). Morris (1993) argued that the largely male-led disability movement in the United Kingdom wanted to focus on winning physical access rights and saw discussion of gender as secondary. So, it was disabled women who began to write about gender, disability and embodiment, conscious that traditional social model theory had to a degree downplayed the ‘disabled body’ as not the appropriate place for gaze or attention. The apparent invisibility of gender in UK disability politics signalled the normativity of male gender within the movement. But within wider society, disabled men were also being characterised as falling short of gender norms. If labour markets, health and education systems were continuing to fail and exclude disabled boys and men, then how could they achieve what a patriarchal society expected of them as breadwinners, home-makers and career-builders? If disabled men’s bodies were affected by chronic illness, pain and/or deterioration, then how could they sustain claims about physical domination, prowess and strength (Charmaz 1994)? If male gender norms meant exerting power over women, then how could disabled men be understood in the context of receiving large amounts of care and support from women in everyday life?

Empirical and theoretical work exploring disability and male gender has not received extensive attention. Whilst there has been a growth in literature and research about men’s health, little of this work has focused on the experiences of disabled men (Robertson and Smith 2012); the focus of the study
here. In a paper which summarises the main theoretical developments in disability and masculinity, Wilson et al. (2010) discuss two important pieces of work in the field: Connell (1995) and Gershick and Miller (1994). Connell’s (1995) description of a hierarchy of masculinities suggested that a ‘hegemonic’ masculinity was the more privileged and sought after. This privileged, dominant and idealised masculinity was predicated on traits such as physical power, autonomy and dominance. Subordinate masculinities were available to those men who could not attain these hyper-masculine ideals; for example, gay men or disabled men. These men were excluded from the hegemonic ideal because of inherent weakness and impairment (a medical model interpretation) or because of society’s barriers and oppressive normative assumptions about what constitutes a ‘real man’ (a social model interpretation). Wilson et al. (2010) made an explicit connection with the social model of disability to highlight the connection between the barriers faced by disabled men and their opportunities to claim masculinity. They argued that disabled men’s masculinity was often seen as ‘diminished’ in part because of masculinity being played out and interpreted within a care-giving relationship from paid support staff - and, we would argue .... etc.

Connell’s account of hegemonic masculinity was interpreted by Gershick and Miller (1997) in relation to disabled men by suggesting ways in which disabled men rejected, reformulated and relied upon hegemonic masculinity. So, these are ways in which disabled men may reject normative assumptions about hegemonic masculinity and make other kinds of sense and meanings about gender which both challenge gender norms and also affirm something different. Reformulating masculinity meant understanding limitations of self and finding different ways of living with and constructing masculinity. Reliance was interpreted as disabled men drawing on hegemonic masculinity to construct their gendered identity. These turns to or against masculinity are akin to the identity dilemmas outlined by Charmaz (1994) and are particularly pertinent for disabled men whose choices are likely to be mediated by other people and structures which either enable or restrict autonomy.

Wilson et al. (2010) point out some of the limitations of these models in that they do very little to understand the differentiated experience of disability; that is, the models and theories assume that most disabled men are the same. They argued that what was lacking was an exploration of what difference the intersection of disability and male gender makes in relation to other identity categories. These might include age or ethnicity or, as in this article, particular experiences of being disabled that might relate to living with a particular kind of impairment or long-term health condition:

The focus of study has been on masculinity and how it intersects with ‘disability’ as an almost generic category, rather than on how masculinity (or masculinities)
Shuttleworth, Wedgwood, and Wilson (2012, 176) note that Shakespeare’s (1999) paper made claims which are still relevant. Specifically, that there is not much empirical research to inform debates about disability and male gender; that ‘real disabled people’ are missing from much of the discussion; and that disabled men have something useful to offer debates about what it means to be a man. Of course, the two identity labels which are the focus of this paper are neither static nor stand-alone. Theories of intersectionality remind us that identities, barriers and experiences of oppression interact and that some people live with a range of identity labels which might give rise to experiences of oppression. As Saxe writes:

... what makes intersectionality unique is the fact that it considers identities as interacting with one another, rather than simply separate identities from which the most oppressed is most salient. (2017, 154)

So, it is as Crenshaw (1989, 1991) suggests, the interaction of these identities which can result in highly differentiated experiences of being. Hirschmann reminds us that the disability label or category is often added on instead of woven into discussion about the layered identities of disabled people:

... disability is more than simply another ‘case’ to be added to intersectionality ... a conception that fails to capture the depth to which various aspects of our identity and situation shape all others. (Hirschmann 2012, 401)

Exploring the intersection of disability and male gender also takes place within other, broader contexts. Barrett (2014) challenges us to expand the disability category and to consider how disabled men’s gender may be situated within the shifting domain of what it means to be a man (disabled or non-disabled) and to continue to ask critical questions about disabled men’s performativity of gender within a feminist paradigm. Coston and Kimmel (2012, 98) question the dominance of a homogeneous label of ‘privilege’ for all men and ask ‘What does it mean to be privileged by gender and simultaneously marginalized by bodily status?’ Of course, embracing difference need not be disempowering. Morris (1993) writes of her dislike of the language of ‘double discrimination’. She argues that this only serves to cement the image of disabled women as leading tragic lives dominated by oppression. Crenshaw (1991, 1242) asserts that the ‘embrace of identity politics’ means that the experience of difference offers something potentially liberating – ‘the source of social empowerment and reconstruction’.

This article attempts to meet some of the key challenges posed by the literature: pay attention to differentiated experiences; hear from disabled men themselves; and draw on empirical data. We situate ourselves as social model of disability advocates but also suggest that disabled people who live with
life-threatening, degenerative conditions such as Duchenne muscular dystrophy (DMD) attest to the fact that disease and impairments can be limiting in and of themselves regardless of the social, physical or attitudinal barriers emphasised in the social model. Carried out by disabled and non-disabled researchers, the study presented here focused on how a particular group of disabled men – men with DMD – interacted with the provision of state-funded social care support in England. The primary question was whether the planning, organisation and delivery of that support worked in ways which took account of and considered male gender, or not. In investigating this, we asked the research participants how they thought about themselves as men and how the world of social care treated them as men, or not. We have written about the second part of that focus elsewhere (Abbott, Jepson, and Hastie 2016). The focus of this article will be to describe and then reflect upon how the disabled men in our study talked about their gender in relation to living with a long-term health condition.

**Duchenne muscular dystrophy**

DMD is an inherited neuromuscular disease which affects almost only males (about 1 in every 3500 births). Over time the condition leads to loss of mobility, curvature of the spine, respiratory difficulties and cardiac failure. In the United Kingdom the mean age of death without specialised treatment was 19 years, but over the last few years there have been dramatic changes in the ways DMD is managed. In particular, those who use ventilation to support their breathing can expect to live to around 27 years old (Eagle et al. 2007). Life expectancy continues to rise as a result of medical intervention, and as a result the current generation of men with DMD are reaching stages of adulthood that were, at the time of their childhood, unexpected and unplanned for.

Recent research in the United Kingdom and Canada suggests that despite these improvements in healthcare interventions, the broader social and psychological support needs of men with DMD are not well served. Instead, there is a continuing focus upon medical needs as opposed to wider needs such as access to work, good quality support, independent living, social and leisure activities, emotional support and opportunities to develop sexual relationships (Abbott and Carpenter 2014; Gibson et al. 2007, 2014; Skyrme 2017). Amidst the challenges of planning for an ‘unanticipated’ adult life, men with DMD may well not have been supported to be and become men either. If transition to ‘successful manhood’ (almost always described in the literature in gender-neutral terms as a ‘transition to adulthood’) is equated with paid work, sexual relationships, financial autonomy, physical and psychological separation from parents and so on, then how do men with DMD,
who face significant challenges in many of these areas, construct their own versions of being a man?

The research

The study reported here was carried out in England during 2013–2015 and was a partnership between researchers at the University of Bristol (UK), the Duchenne Family Support Group (a charity supporting families affected by DMD) and Dr Jon Hastie, an activist living with DMD and the chair of DMD Pathfinders, a user-led organisation of men with DMD. The study was funded by the School for Social Care Research, part of the National Institute for Health Research, and ethical approval for the study was obtained from the National Social Care Research Ethics Committee.

Twenty men with DMD were recruited to the study with the support of our partner organisations and via muscular dystrophy-related Facebook pages. The participants were from a whole range of geographical locations across England including both urban and rural settings. They ranged in age from 21 to 33 years; 17 were White British, two were Asian British and one was Black British; one participant was married with children; one identified as a gay man; and one participant identified as a person with intellectual disabilities. Other variables we purposefully sampled for were living situation and primary source of care and support. Eleven participants lived in the home of their parents, seven lived independently and two lived in residential settings. In terms of support and care, 13 had some kind of personal budget (whereby the State gives disabled people money for support that they are then in charge of) and employed their own support workers or personal assistants, three had agency staff organised by their local authority (council), two received their support from the staff in their residential setting and two received their care exclusively from family members.

The study was qualitative involving face-to-face, semi-structured interviews. As a research team, our expertise was in qualitative approaches and we wanted to uncover stories with layered and rich meaning which we did not think would be captured by quantitative methods. Our choice of semi-structured interviews was also partly based on our previous studies with the same group of men. This approach lends itself to research encounters which have a central aim (in our study, finding out about the intersection of social care, disability and male gender) but which also allows space to explore related topics that are of interest to the interviewee or that arise as the interview progresses. As McIntosh and Morse (2015) note, semi-structured interviews can be thought of as ‘… unique among interview methods for the degree of relevancy it provides the topic while remaining responsive to the participant’ (p. 1). In a slightly unusual move we sent participants the
interview guide in advance of meeting them. The guide had been developed having reviewed the literature in the main domains of disability/male gender/social care. It was piloted with two participants and changes made in the light of their feedback and research team discussion. We sent the topic guide in advance for three main reasons. Firstly, we wanted to explicitly flag that we would ask so-called sensitive questions about sex and masturbation. We knew from previous work that this was an area of concern for men with DMD (because of loss of hand function) and we wanted to know whether or not this was something that social care staff were helping support them with. Secondly, as a research team we felt that being asked questions such as ‘What kind of man would you say you are’ was quite difficult and required some thought in advance. Finally, we wanted in some way to give the participants some power in a process in which the interviewer is often largely in charge (Jepson, Abbott, and Hastie 2015). Schwalbe and Wolkomir note the potential gender dynamics involved in research interviews:

To agree to sit for an interview … is to give up some control and to risk having one’s public persona stripped away. Surplus threat can arise from questions that might expose the masculine self as illusory. (2001, 91)

We carried out face-to-face interviews with 20 men with DMD aged over 18 years. David Abbott at the University of Bristol carried out two thirds of the interviews and Jon Hastie carried out a third. All of the interviews took place in the participants’ homes, and were digitally recorded with consent and then fully transcribed. Interviews lasted between 36 and 106 minutes with the average length being 65 minutes. Participants were given a £20 gift voucher in recognition of their time and contribution. After the first two interviews we had the transcripts immediately transcribed and met as a team to review them to see whether we felt the topic guide was continuing to work well, and crucially to see how both interviewers were managing so-called ‘sensitive questions’. We did this using conversation analysis (Sidnell and Stivers 2012) to look at small extracts of talk which had a focus on masturbation. Early analysis revealed that these questions were being handled poorly. This early analysis forced the interviewers to adopt a much a more consistently confident approach to every part of the topic guide.

We carried out data analysis in two different ways. Firstly, the lead researcher carried out an initial thematic analysis (Braun, Clarke, and Rance 2014) of the data, which were interrogated to find text and talk that answered the primary research question (and the one of most concern to the funder) about whether the organisation and delivery of social care took account of the participants’ gender – or not. In addition, the anonymised data were shared across the wider research team and each member was tasked with looking at the data with a specific lens matched to their area of expertise: key messages for social care, social work and social workers; an
‘insider view’ of the data based on lived experience of DMD; using conversation analysis to look for ways in which the organisation of talk in the interviews revealed particular meanings; how the data developed our understanding of theory in relation to disabled men and gender; and an analysis which focused on the narratives and stories that were being told about being a man in the interviews. Colleagues were sent a selection of transcripts in advance of a two-day analysis meeting in which we shared and discussed our analyses. Using this approach was helpful as it drew on different kinds of expertise and revealed additional nuances and complexity in the data.

Findings

Within face-to-face interviews, research participants spoke on a variety of topics that pertained to their lives as men in relation to the labour market, relationships including sexual relationships, their bodies, the organisation of care and support. We asked only a relatively small number of direct questions about male gender which were along the following lines: what kind of man would you say you were? In what ways do you think of yourself as similar or different to other men? Do other people in your life treat you like a man, or not, would you say? As mentioned earlier, we had signalled our intention to ask these questions by sending our questions in advance. The data described in the following focus on three themes: sense of self as a man; similarities to and differences from ‘other’ men; and sex and relationships.

Sense of self as a man

One of the reasons why the construction of manhood is especially interesting for men with DMD is that, as mentioned, most adult men with Duchenne would likely never have expected to live into manhood. At diagnosis, parents were likely to be told a variance of ‘Go home, enjoy your boy, have nice holidays and prepare for the worst’. So, we were interested in what participants had to say about a state of being – adult men – that may have been both challenging and surprising to them.

A positive sense of being a man was often equated or intertwined with having a high degree of choice and control over everyday life. Those that described more agency, sometimes couching it in terms of feeling manlier, were by and large more in control of day-to-day support (with washing, dressing, physical care, support to go out in the community, etc.) from non-family members. This usually meant employing, managing and directing support workers for a certain number of hours per week (ranging from a small number of hours to 24 hours a day):
It makes me feel more of a man because I’m managing my own life. I’m managing other people and actually providing jobs for eight people.

Good support arrangements could be transforming. One man also selected the support staff that he wanted:

I want to do what I want to do, just like anyone else. Having choice and power over that, it makes me happy. It’s a simple word to use for how it feels. They are not just to keep me alive, but they’re there to help me get the most out of life that I possibly can.

Several of the men cited important achievements that had bolstered their sense of selves, as with the following man who had become a campaigner for a charity working towards better access and support for other young disabled people:

The first time I felt like a man was when I did that speech about the [inaccessibility] of cinemas. I felt kind of important, that people were listening to me. It helped me re-evaluate my life and actually understand what manhood is.

The development and visibility of adult role models with DMD helped considerably in establishing masculine identities. Several men talked about how important it was to realise that they would live into adulthood and become and be men:

Meeting other men with DMD, well you think, they’re a man so I can be a man too. You see some and they are a bit weaker than you but achieving more than you so you kind of have to grow up and think, just be a man gracefully, like they’re doing.

Whilst being disabled often elicits a tragedy narrative or one in which disabled people are considered to be inspiring just for being alive (Grue 2016), it is possible to subvert this narrative and think about ways in which living with DMD and significant medical intervention leads to the accrual of maturity and wisdom. This was how one respondent framed an answer to our question ‘What kind of man would you say you were?’:

Brave. People keep saying to me that they didn’t know how I stayed sane having been in hospital so long. I just kept thinking about once I got fit, I could go home again and try and get back on track.

Opportunities to go out into the world can be restricted by physical inaccessibility of buildings, the extra costs associated with travel and the availability of people to go out with. These restrictions can have a profound impact and many of the participants referred to mental health problems associated with loneliness and frustration. One man had a personal assistant paid for by public social care for 16 hours a week. However, a lot of that time was spent on washing and dressing with very little time to go out and enjoy life. He was extremely frustrated by this and wanted to someone to take him out to pubs, something he equated with ‘... things other men do ...’:
They don’t realise what I’m missing out on by missing those hours. I’d go out a lot more. It would help a lot.

Others said that the foregrounding of their disability label or identity by social care funders and services over any other identity created unhelpful assumptions which prevented them from leading fulfilling lives:

They focus on the healthcare aspects. They don’t see you as a social person at all. I have to fight to get social hours. It’s like all that matters is that you get cared for. Going out or having a social life is secondary. If it’s all about healthcare that’s what your life becomes.

The ability to separate from carers as adulthood emerges can be complex for men with DMD. Very enmeshed relationships with carers, often mothers, are usual all through childhood. One man described how having support that he was in control of meant that his mother was no longer his primary carer. As a result, his relationship with her and his sense of autonomy had both improved:

I can do what I want. Not have to sit through Mama Mia and be told off for not enjoying it! My mam was my primary carer. And you fall out. Especially as a teenager. You don’t want your mam to see some of the stuff she’s seeing. I wanted my mam to be my mam, not my carer.

Living independently can be one important marker of adulthood. Those men who had moved out of the family home (about a third of the men in our study) described the benefits:

I think it’s given me my own life really which wouldn’t have happened if I’d been stuck at home. It’s much healthier from a psychological point of view. I suppose I became an adult really.

For one of the Asian participants, there was no expectation that he would move out unless he was married. He had distanced himself from his extended family who he said had no expectations of him ever being married – ‘How can a disabled person be a man, they say’. He was happy to stay at home and described a way in which he had maximised independence without moving out:

I feel more comfortable at home. I think you can live independently at home, it’s just a mind-set. I think it’s your mind you have to make more independent, you don’t have to physically move out.

Only one participant was a father and we went to some efforts to include him in the study in part to let the wider DMD community know that it was not an urban myth that you could be a father with DMD. We were also interested on the impact of fatherhood on ‘sense of self/manhood’. We asked him what it was like to be a dad:

Scary, but really good at the same time. He’s [son] healthy and full of energy. I worried a lot about how long I would be around, so I’ve set myself a goal to
survive till I’m 40. That is the goal I’ve set myself. I really enjoy being a father, it gives me a purpose because he [son] always wants me about. It just makes me feel grown up, manly, like.

We heard of many examples when the decisions of others, or the characterisation of participants in a way that was infantilising, worked to diminish a sense of being an adult man.

The other day I was out in a shop buying a game and the bloke said, ‘Where’s your mum, you’re normally with your mum?’ I thought, my god this guy thinks I’m a kid or something.

Sometimes they [support workers] treat me like their children or something. One lady brought me a toy turtle and said, ‘I thought you looked like a turtle when you were in bed.’ It’s like, really?!

**Similarities to and differences from other men**

A strong theme in the data was men discussing the ways in which the participants were similar and different to other men. These focused on being similar to other, non-disabled men in terms of interests and aspiration, and being different to other, non-disabled men in terms of particular challenges they faced. Similarities and differences were of course not always neatly compartmentalised:

In general – I think mentally I’m similar, but physically a bit different. Really, I just think of myself as a normal bloke.

The participants all spoke of their commonality with other men especially in relation to interests and hobbies such as sport, music, films, computers, gaming and friendships. Other bigger aspirations were also shared. These included moving out of the family home, getting married/partnered and having a family:

I think I’m a regular bachelor. I want a family for the fulfilment really. It feels like happiness, like it’s a dream. That’s all I ever want really, go shopping, get married, look after the kids, try to work, be a regular guy.

Differences from non-disabled men related primarily to the physiological aspects of DMD and opportunities to have sexual and romantic relationships as well as societal barriers and prejudices. These were often inextricably linked; that is, participants suggested that sexual partners may not be interested in them because of their bodies and appearance:

I think women don’t always see you as a potential partner. The stereotype is you have a man who looks after you, someone big and strong. So, it’s a bit tricky and if you’ve got a severe muscle disease, it’s a bit difficult to have confidence with women.
The gay man in our study acknowledged that the commercial gay scene was not welcoming of bodily diversity. He wanted to challenge this simply by being present in those spaces and not absenting himself:

I think as I’ve got more confident I almost want to place myself in these places to say, ‘Look, see, I’m here, this is normal, get used to it’. Making a bit of a figure of myself to make a point really.

Some men did feel that they would struggle to be the protector in a sexual relationship, a role which they either felt they should be able to adopt or one which gender norms might expect them to occupy:

I don’t feel like a good man really. Like my appearance and my weight. Like the man or the father is supposed to be the protector, but I could never be that.

The day-to-day health-related effects of living with DMD were described as restricting in ways which marked out differences with non-disabled men:

My goal is to survive really and keep myself healthy. Whereas the average man wouldn’t have to worry about being healthy, they’d just get on with the other things they have to do.

Some men challenged (one might say reformulated) what they saw as outdated versions of manhood, especially in relation to physical strength and the accumulation of muscle. One man reflected in the interview on his sense of having developed a lot of emotional and mental strength in large part because of the challenges associated with living with DMD. He repudiated the idea that he was somehow less of a man for his lack of muscle:

A man isn’t defined by his muscles, he’s defined by how mature he is. I think being strong mentally is better than being strong physically and pretending.

Other men distanced themselves from what they saw as oppressive stereotypes of masculinity:

I’m not as independent as some men, I can’t do the same sort of things, but then I wouldn’t want to. I don’t like drinking or clubbing. I’m more of a bookworm, a geek.

I was always quite envious of muscular men. I’ve never been a very masculine or macho person. I think I’m quite a soft person. Sort of laddish culture, I’ve never really been a part of that.

The same man had interesting things to say about how his views on the need for support had evolved. Where once he had seen this as a sign of weakness, he had come to see that embracing the need for support was indicative of his maturation:

When I first had carers I didn’t like them, I felt kind of exposed. But now I think I’m disabled and I’m a man and you’re more of a man if you accept that you need help. That’s a strength, not a weakness.
**Importance of sex and relationships**

As well as a site for establishing similarities and differences with other men, sex and relationships played a key part in descriptions of living as a man with DMD. Discussion about this took up large parts of the interviews. Only a small number of the men in the study were in relationships, or had ever had relationships. Those who had spoke about the joys of intimacy:

> It was the first time that I’d been shown affection, so that was quite important. Sort of like the closeness of being with someone, just lying next to them. And feeling that someone … feeling wanted, I suppose.

> It helped my confidence a bit because before that I was sort of under the impression, why would anyone be interested in me? So, to have it felt like a connection, or maybe love.

Current or previous relationships could be fragile insomuch as participants often relied upon other people to help them to be with partners. Some did not survive gaps in distance, for example:

> I was engaged for a while, but the distance thing was really difficult, and I didn’t have any carers who could drive. So that was it. Reliance on other people, basically. That’s all I’ve got to say about that really.

One of the men with intellectual disabilities who lived in a residential setting wanted support to do many and various sexual activities, He elaborated on these once his mother had left the room:

> I’m a big fan of the ladies. I do like pole dancers. I want a girlfriend if I can get out of this place. I just want to have a good relationship.

The physical support needed to be with a sexual partner was an issue and often a perceived impediment. Most men would require their partner to physically move them to be in sexual positions or they would require a support worker to help. This would require all parties to be happy and confident with the arrangement:

> I’d need a lot of help to say, recline and do pretty much everything. So, I don’t know how that could happen unless someone could help me which would be a bit awkward.

One man who was in a relationship said that he would need physical support to have penetrative sex with his disabled girlfriend. His girlfriend was not willing to do this:

> We’re not able to do that. She’s disabled too and it’s hard for her to move for both of us. I would love to, but she wouldn’t feel comfortable with getting help. I wouldn’t mind, I’m a man. But no, she wouldn’t be comfortable with that.

The loss of hand function for men (associated with the later stages of DMD) meant that most participants could no longer masturbate. This was a
source of considerable distress for some and a topic that very few had felt able to discuss with anyone. The fact that a myriad of health and social care professionals had never mentioned the topic whilst discussing so many physiological aspects of living with DMD spoke to us of the gender-less, sex-less construction of these men by many in their lives.

I feel like I have quite a high sex drive which is frustrating because there’s nothing I can do with it generally. I used to be able to manage [masturbation] by myself but in the last couple of years I haven’t been able to … so it’s like you can’t do it.

About a third of the men in the study had had paid sex with sex workers (male and female). Another third said they were thinking about doing this and the remaining third said they would not consider it. None of those who had been with sex workers said that this had been their first choice: ‘I’m glad I did it, but it was a bit empty’. Some of the men were grappling with very mixed feelings about the issue:

I’ve thought about it, but I’ve never done it. It seems a bit wrong, almost like a commodification. I’m not saying never.

And some were clearly not interested in the idea at all:

I don’t want a prostitute or something like that. That’s not the way I would want to do that. That would be meaningless to me.

There were no opportunities to make these choices privately or in isolation from other people’s support. One man said he knew his parents would not approve so it was not an option for him, ‘… even though it would be a good thing to experience’. Another man who also lived with his parents did discuss it with them and they agreed that they would go out when the sex worker came over. He was very positive about his experience:

She was very nice to me and asked me if there were no-go areas or things I’d like to experience. She’d had disabled people before, so she was quite experienced. It was like a fulfilment if you know what I mean. Made me more confident because I’m not a virgin anymore.

**Discussion and conclusions**

We have presented just some aspects of data from a rich set of qualitative interviews. Some of what we have written may seem trite and obvious (e.g. the disabled men in the study felt similar in many ways to non-disabled men). Unfortunately, our broader findings suggest that this point still needs to be made. Men with DMD lead highly medicalised lives (Abbott and Carpenter 2015) and, partly because of cuts in social care spending in the United Kingdom which restrict liberty and participation (Goodley, Lawthom, and Runswick-Cole 2014), being alive is sometimes deemed to be good
enough and scope for other identities is limited. As Gibson et al. (2007) suggest, men with DMD have yet to be considered as ‘legitimate members’ of society, in part because of ‘the current disjuncture between “saving” persons’ lives using sophisticated technologies and establishing the means for them to participate in their communities’ (p. 516).

A complicating factor throughout this field of enquiry is the difficulty in teasing out how disabled men might be denied adult status let alone a gendered identity. The practice of ableism often robs disabled people of an adult identity and our findings reveal instances of men being infantilised as assumptions are made about cognitive and physical abilities capacities. Liddiard and Slater (2018) suggest that this speaks to society’s need to distance and remove itself from the ‘threat’ of bodies which are non-normative, and which need to be ‘contained’ and which deeply unravel our ideas of what development over the life course should look like, physically and metaphorically:

Containment … is an expectation of normative adulthood, which results in the oppressive infantilization of those not meeting up with the (contained and containable) raced, cis-gendered, heteronormative and dis/ableist expectations of what it is to be an adult. (Liddiard and Slater 2018, 321)

Our study reveals ways in which men with DMD think about what it means to be a ‘good’, ‘regular’ or ‘normal’ man and we hear accounts of achievement, failure and ways of resisting and/or modifying so-called classic markers of successful manhood. For some there was clearly a wish to establish commonality of interest and identity with other (usually non-disabled) men – the references from some to doing ‘blokey things’: sport, gaming, technology, sex – but also traits such as confidence, courage or a sense of humour. Going out at night and drinking seemed of particular significance to some but was often logistically difficult (Mitchell et al. 2017). The focus on being a ‘regular guy’ may in men’s minds narrow the gap in terms of aspects of manhood that do not seem readily available, a finding that resonates with similar work with Canadian men with DMD (Gibson et al. 2014):

… narratives of non-difference reproduced by participants served to distance them from the atypical aspects of daily life and diminish inconsistencies with the identity of a ‘normal guy’ (p. 108).

There are scattered claims in terms of non-hegemonic masculinities, but they are still much in evidence: reformulating how accepting help with support workers is a sign of maturity; recognising that emotional intelligence may be on a par with or more important than physical strength; and acquiring courage and wisdom via the adversity of prolonged hospital stays and medical interventions, for example. We also see paradigm examples of how some men defined ‘normal adulthood’ as a man – descriptions of wanting to
get married, have a family, look after children and lose virginity. What Coston and Kimmel (2012) describe as ‘normification’ entails some disabled men finding ways to exercise dominance in the context of a wider society which ‘… stigmatises them as not-men’:

If you have even a small amount of power you might try to minimise the differences … it involves exaggerating the similarities and downplaying the differences. (Coston and Kimmel 2012) (p. 100)

In terms of gender relations, we see a fairly full range of attitudes towards and about women: wanting to be a protector; wanting to be seen to be sexually active; and reflecting on what a woman (or man) might expect from a body. However, we also hear from men who have had very close and important relationships with women all of their lives: firstly, with mothers as primary carers and then with support/care staff who are predominantly women. Men offer, as in Gershick and Miller (1997), the triad of responses to hegemonic masculinity; that is, rejections, reformulations and reliance. They also offer, as Shakespeare observed in his work, some learning and wisdom that are useful to non-disabled men:

… [disabled men] could profitably share insights into gender relations, sexuality and particularly issues of physicality and the body. (1999, 63)

On the issue of sex, romance, intimacy and relationships, our co-author who lives with DMD reflected that one of the biggest challenges associated with DMD is the acceptance of change, deterioration and loss of ability. ‘Life-span issues’ play a considerable part in how men might respond to their lives, with long-term goals being harder to set as the uncertainty of life expectancy remains. So, sex may well become a milestone rather than an ongoing activity. Aspirations for pleasure and relationship may sometimes be subjugated to the desire to have sex as an achievement before death (Tepper 2000). Some men who felt that heterosexual sex and relationships were not going to be available to them reframed their own position and rejected the primacy of one kind of sexual activity:

I think society and being a man … it [sex] is necessary. That’s kind of what an adult is. Your relationships change and you need to advance. But other people advance in different ways to me. I can have just … like friendships. You have to adapt to differences.

The issue of sex workers and disabled men is a contentious one and is explored in the depth it deserves by others (for example, see Liddiard 2014). What the issue reveals here is the ways in which men in our study were often completely reliant on others to do gender/to do things as men. This could be a physical reliance: enough funds to pay for support workers to take them out into the world; and a reliance on the attitudes and permissions of others – will a parent agree to a sex worker coming to their home,
will a support worker agree to facilitate someone going on a date with someone of the same or opposite sex, for example (Browne and Russell 2005)? The conditionality of access to manhood is at odds with the rhetoric of the human and legal rights ascribed to all disabled people to participate fully in their communities, and we see the disjuncture acutely here.

Life course/span issues are, as we have mentioned, acutely felt by men with DMD for whom normative assumptions about time can be potentially quite disabling. We certainly hear of adaptations in behaviours and expectations over time from the men in our study – ‘I enjoy photography. I used to draw but then I lost the ability to draw. So, it’s a way I’ve found of expressing my emotions’. Shuttleworth, Wedgwood, and Wilson remind us that the changing nature of impairment over time is under-explored and that perceptions of manhood in later life (whatever number of years that is) opens up different intersections between gender and impairment and disability:

The dynamism of disabled masculinity becomes most apparent in research that focuses not only on changes from one socio-historical context to another but also the changes that can occur from one life-phase to the next … (2012, 185)

Our data show the usefulness of research with disabled men which differentiates along lines of condition, disease or ‘impairment’. The experience of a man with Duchenne in his 30s who wears a ventilation mask full time may struggle to leave the house in winter months for fear of catching a (lethal) chest infection, who may well be in the last years of life and who was never expected to reach manhood is, of course, likely to be different (as well as similar) to men with acquired impairment or significant learning/intellectual disabilities and so on. Even within a relatively small group of respondents we also see other intersecting aspects of identity such as culture, sexuality and parental status that mediate experience. That said, we recruited an overwhelmingly white and heterosexual group of respondents and only one with intellectual disabilities, and it is not to our credit that we did not particularly problematise this during the research. The demographics of our respondents largely reflect the membership of the groups from which we recruited. This raises important questions about how boys and men with DMD from a range of minority backgrounds access information and peer support. This is a particular limitation of our study, especially given data which suggest higher rates of neuromuscular disease amongst minority ethnic communities in the United Kingdom (Woodcock et al. 2016).

A cautionary note. This article reflects some challenging aspects of life as a man living with DMD. This can sometimes be a trap with social research that takes as its starting point (as ours did) doing research which benefits those who are the focus of it. So, there is political capital in highlighting the shortcomings of support for disabled men which we have argued elsewhere may emasculate and disempower them. But this runs the risk of being a one-dimensional portrait which falls into the trap of creating a tragedy-narrative about the lives of
men with DMD and other such life-shortening health conditions. In our data we see intersectionality operating as a way which differentiates (Crenshaw 1989, 1991; Sawyer, Salter, and Thoroughgood 2013), oppresses (Liasidou 2013) but also liberates (Crenshaw 1991; Hirschmann 2012; Morris 1998) the men in our study. Male gender is not an identity label horizontally sliced and on top of or below a disability label on any given day. It remains problematic that doing gender for disabled men can still be so reliant on the availability or permission of others. It remains liberating to highlight that the difference created by men’s intersecting identities also allowed them to, at times, redefine notions of gender, masculinity, independence, life course and wisdom. Dhanda (2018) points to the potential of looking at intersectionality as:

… something distinct from discrimination, as a separate conceptual category. If we speak about intersectionality as a tool for social change, we cannot restrict it only to the realm of multiple discrimination.

Throughout the study we found evidence for the agency, determination and sometimes resignation of men organising their lives in spite of a precarious and unanticipated life course. We have attempted to foreground their voices and, as part of the wider study, worked with a film-maker to produce a widely distributed short film highlighting the nuanced, complex and multifaceted lives men with DMD are living (Sobers et al. 2014). Life as an adult man with DMD is a life worth living (Hastie 2012). 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.

Acknowledgements

The authors are very grateful to all of the research participants. This article reports on independent research funded by the NIHR School for Social Care Research. The views expressed are those of the authors and not necessarily those of the NIHR School for Social Care Research or the Department of Health & Social Care/National Institute for Health Research (NIHR).

Disclosure statement

No potential conflict of interest was reported by the authors.

ORCID

Barbara E. Gibson http://orcid.org/0000-0003-0429-8679

References


Dhanda, Amita. 2018. “Intersectionality as a tool of social change.” Paper presented at Centre for Disability Law & Policy, National University of Ireland, 10th International Disability Law Summer School, Galway, June 18–22.


