

Men living with long term conditions: exploring gender and improving social care

KEY FINDINGS

- Social care in its broadest sense did little to support a positive sense of masculinity or male gender (with a very small number of exceptions) for men with Duchenne Muscular Dystrophy (DMD) who took part in this study. More often than not the organisation and delivery of social care de-gendered many of them. Gendered needs around personal care, social opportunities, empowering interactions with social care organisations and staff, sex and sexuality were almost never addressed in assessments, support planning and reviews or in day to day practice.
 - Participants described a strong sense of male identity typified by phrases like, “I think of myself as a normal bloke”. They also talked about constructions and perceptions of being a man which arguably challenged general male stereotypes in a positive way. For example: maturity and self-awareness mattering more than muscles; understanding that being a man with DMD necessitates care and support; achieving states of independence (physical or mental) which may not necessarily involve moving out of the family home; emotional strength and maturity developed by facing some of the trials and challenges associated with living with DMD.
 - Participants offered accounts of their similarities to, and differences from, stereotypes of ‘ordinary’ (usually non-disabled) men.
- Areas of similarity included:
- being and wanting to be sexually active;
 - cultivating self-esteem through academic achievement, work and rewarding activity;
 - hobbies and interests such as sports, drinking, computer games, technology, art and design;
 - being a father (as one participant was);
 - living independently and/or owning a home.
- Areas of difference included:
- difficulties in attracting sexual/intimate partners;
 - barriers to obtaining paid work;
 - concerns about moving out of the family home relating to care, support and loneliness;
 - restrictions on a social life linked to shortage or inflexibility of support arrangements;
 - physical appearance and muscularity (for some linked to a concern about not being able to ‘protect’ current or potential female partners).
- One of the most commonly discussed aspects of manhood related to intimate relationships, including sexual ones. While some participants were or had been sexually active, most were not. Because of loss of hand function many could not masturbate and found it too sensitive a subject to raise with support staff. Only one participant could recall any

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social care professional talking to them about sex and most (though not all) said that they would welcome such conversations. Two-thirds of the men had used, or were contemplating using, sex workers, though this was considered largely as a last resort. The use of sex workers usually required the active co-operation of parents and/or paid carers/support workers.

- The research team were initially unsure how easy or difficult it would be for participants to talk about: (1) being a man (not necessarily an everyday topic of discussion for any men); and (2) sensitive topics such as sex and masturbation. Two things helped. First, the interview topic guide was sent to participants in advance. Second, close analysis of interactions in early interviews revealed that researchers' own anxieties about sensitive topics were being projected in the tentative way that questions were being asked. This was remedied. It was also apparent that researchers' anxieties were largely unfounded and that participants were willing to talk openly about their experiences.

BACKGROUND

Many people with long-term conditions are living longer due in large part to advances in medical technology. Gibson *et al.* (2009), however, found that people's broader social needs are not always so well supported – things like help to find work, getting good quality support, having help to maintain a good social or cultural life, or pursuing intimate relationships. Men who live with DMD (see box) – a life threatening, long-term condition – are one such group. Abbott and Carpenter (2014) suggested that once this group of men have finished at school, college or higher education, many have no meaningful day-time activity and reported high levels of social isolation. The research reported here focused on this group of men as an example of just one group living with long-term conditions for whom good quality social care is important.

This research focused on gender, based on the hypothesis that the impact of male gender is rarely addressed in planning and delivering social care (e.g. in support planning meetings,

DUCHENNE MUSCULAR DYSTROPHY

DMD is an inherited neuromuscular disease which affects males (in about 1 in every 3500 UK births.) By the age of 13, boys with DMD have generally lost the ability to walk independently. By the mid-teens there are other complications: curvature of the spine, respiratory difficulties and cardiac failure. For young people with DMD, the years between 15 and 20 are likely to mean further spinal surgery and decisions about the use of assisted ventilation for respiratory management. The mean age of death without specialised treatment was 19 but during the last few years there have been significant improvements in the way DMD is managed. In particular, teenagers who have been using nocturnal home ventilation to support their breathing can expect to live to around 27 years. The mean age of death is continuing to rise as more effective medical interventions impact on the current generation of men who are reaching stages of adulthood that were, at the time of their childhood, largely unexpected and unplanned.

reviews, in organising and managing support workers or personal assistants). It is possible that men living with DMD are not routinely regarded as 'real men' by those around them because of their increasing reliance on physical support, the physical change and deterioration in their bodies and the barriers they can face in achieving satisfying adult roles (e.g. jobs and sexual relationships). If in 'mainstream' society, being a 'successful man' often means things like having a job and money, not living with parents, having sex and intimate relationships, having a car or displaying physical strength or prowess, then what do men with DMD who face significant barriers in many of these aspects of life, think of their own manhood and masculinity? Do social care staff discuss and support gender-related issues with men they support and work with? If not, how could this happen or how could it be better? This study aimed to answer these questions.

FINDINGS

In the organisation and delivery of social care the men in this study reported being treated as largely gender-less. Examples of this included little or no discussion in assessment, planning, review, practice or on-going interactions with the range of social care staff

about things such as: intimate and sexual relationships and the physical and emotional associated challenges; the gender preferences of staff/carers; psychological needs in relation to body image, physical decline, loss of hand function, use of steroids; and, how restrictions on funding and availability of support staff to facilitate a social life and community participation heavily restricted men's sense of agency and manhood:

They seem to be completely gender-less – it's not even gender neutral, because gender's not even in there. It's asexual, basically, approach to social care, in my experience. I think the actual impact of social care can be incredibly emasculating, if it is set up in such a way that it takes away your independence and your autonomy, that is incredibly emasculating.

There were examples of men experiencing patronising interactions and perceptions including: assumptions by a range of health and social care professionals that the men would not be interested in fatherhood, marriage or that, if sexual, they would be heterosexual; men being given soft toys and called 'love' by older, female carers:

A lot of the [agency] people work with children. So this one lady because I was in bed, and I was ready to get up, and I was just lying there, she said, 'You look like a turtle, sitting there.' She got me this stuffed turtle for my birthday! It's like, really? She was sort of like, 'Turtle, turtle.' I think that's alright if you work with children, but...

There was an obvious inaction or avoidance of the issues of sex and relationships on the part of many professionals. 'Doing' sex, masturbation or achieving states of intimacy with others requires discussion, openness and often, physical support. Those who were no longer able to masturbate described significant mental and physical frustration:

I do feel sort of frustrated that I can't do anything. There's no outlet to relieve the stress of that. I have sort of brought it up with staff but they're a bit clueless as to what to suggest. I try to broach the subject but it's difficult without staff feeling they're crossing a line. Sometimes I worry if someone did help then they'd think it was abuse. I think people assume we can't consent to things. I don't see how it's a

problem if all parties say yes. I understand they mean well...trying to prevent abuse... but it's not always as black and white as people in authority would like to think.

Despite any preconceived ideas about men being open and willing to talk about so called sensitive subjects with professionals, most participants said they wanted cues and opportunities to broach topics such as sex:

It would be good in general, in the care industry, if they thought about these things more. Things about sex, which are important to people. Relationship things. It might be just me, and if I did talk about it, it would be fine. But it has to come from both you and the agencies. It would be valuable. But it's not something they obviously think about at all. If they were more open about it, it might be easier for me to talk to my carers about. It might make it easier to be open about it if they were.

There was a strong correlation between feeling like a man and the degree of choice and control participants had over their everyday support:

Making decisions about the support I get is really important. It gives me more power and makes me feel...yeah. But I am in control, it is my – I mean it's my life, so.

I think my sense of being a confident, successful man has only really come about to a real extent since I've moved out and had the 24-hour care package, which has allowed me to be completely independent.

Men reflected on the whole range of adversities associated with living with a degenerative, long-term condition: major medical interventions, physical pain, significant bodily, and psychological adjustments. While these are often viewed by wider society as reasons to either sympathise with or pity men with DMD, they can also be seen as ways in which wisdom, maturity and insights are acquired:

I'd describe myself as a brave man. A man isn't defined by his muscles, he's defined by how mature he is.

Because I'm disabled and I'm a man, I think you're more of a man if you accept you need help. That's strength. I think men use tools and stuff. Carers are like the tools to help you in your life really.

CONCLUSIONS

Arguably, there are important messages for social care arising from this research, but who are the social care actors we are talking about? As with previous research with boys and men with DMD, social workers are almost entirely absent and, despite reported high levels of mental health needs, the listening professions are rarely engaged either. So, in this context the field of social care professionals and agencies are quite disparate mainly focusing on personal assistants, agency staff, and care managers. It is important for the social care sector to think about gender and the whole range of social and sexual needs men living with long term conditions may have. These so called 'sensitive topics' need to be initiated by staff thereby giving explicit cues that the topics are legitimate and important. Men with long-term conditions may also need to self-organise and empower themselves so that they can teach the social care professionals they encounter about the importance of gender and their identities as men. This looks more possible as adult role models with DMD organise (e.g. www.alifeworthlivingfilm.com), user-led organisations begin to emerge (e.g. www.dmdpathfinders.org.uk), and social media sites provide opportunities for supportive interactions.

Men with DMD are not representative of all men living with long-term conditions. What may be generalizable is the experience of living with a medical label first, as a person with a wider range of needs second, and possibly as a man third – or simply as a genderless person. In addition, the challenges associated with carving out a fulfilling adult 'role', whether that be work (paid or unpaid), training, education etc. might undermine perceptions of being a man or a 'successful man' if good support is lacking.

References

Abbott D, Carpenter J (2014) 'Wasting precious time': Young men with Duchenne muscular dystrophy negotiate the transition to adulthood, *Disability & Society*, Published online June 2014.

ABOUT THE STUDY

The study took place between October 2012 and April 2014 and was based at the Norah Fry Research Centre, School for Policy Studies, University of Bristol. David Abbott and Dr Marcus Jepson at Bristol worked with Dr Jon Hastie (a researcher and activist living with DMD) and the study was also supported by the Duchenne Family Support Group as well as Professor John Carpenter, Dr Barbara Gibson and Dr Brett Smith.

20 men aged 18+ with DMD were recruited to the study in 2013 with the support of the Duchenne Family Support Group and via muscular dystrophy related Facebook pages from a range of geographical locations across England including both urban and rural settings. They ranged in age from 21 to 33; 17 were white British; 1 participant was married with children; 1 identified as a gay man; 1 had a label of intellectual disabilities.

Other variables the project team sought to purposefully sample for were living situation and primary source of care and support. 11 participants lived in the home of their parents, 7 lived independently and 2 lived in residential settings. In terms of support and care, 7 had direct payments or personal budgets and employed personal assistants, 6 were in receipt of continuing health care funding, 3 had agency staff organised by their local authority, 2 received their support from the staff in their residential setting, and 2 received their care exclusively from family members.

Face-to-face interviews were carried out with the men and analysed using thematic and conversation analysis.

A short film based on the research findings made with Shawn Sobers and others is available at: www.youtube.com/watch?v=5VBcHUZ1xrg.

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Ethical approval for the study was obtained from the Social Care Research Ethics Committee.

Gibson B, Zitzelsberger H, McKeever P (2009) 'Futureless persons': Shifting life expectancies and the vicissitudes of progressive illness, *Sociology of Health & Illness*, 31, 4, 554–568.

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