

Supporting men with long-term conditions

Outline of a research project
funded by the NIHR School
for Social Care Research



Improving the evidence base for
adult social care practice

What gender specific challenges and support needs are faced by men with long-term conditions?

Many people with long-term conditions are living longer, healthier lives due in large part to advances in medical technology. Research has found, however, that people's broader social needs are not always so well supported – for instance, when help is needed to find work, maintain a good social or cultural life, or to pursue an intimate relationship.

Men who live with Duchenne muscular dystrophy (DMD), a life threatening, long-term condition, are one such group. Existing research suggests that once this group of men has finished at school, college or higher education, many have no meaningful day time activity and report high levels of social isolation.

In this context, the role of gender – here male gender – is rarely addressed in planning and delivering social care, for instance in support planning meetings or when organising and managing support workers or personal assistants. It is possible that men living with DMD are not routinely regarded as 'real men' 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 in jobs and relationships.

This project

- will explore how social care support does or does not address male gender issues and highlight ways in which care staff could improve and sustain the wellbeing of men with long-term conditions.

It aims to

- understand how men with a long-term and life threatening condition (in this instance, DMD) understand their identity as men and how their gender is, or could be, supported by social care
- improve social care professionals' understanding of, and approaches to, issues of male gender and thereby improve outcomes for service users
- gain insight into how user involvement in research may or may not affect the 'co-production' of a research encounter (in this instance about gender and living with a long-term condition) – and arguably therefore other encounters with social care staff.

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WHAT IS THE CONTEXT?

Several groups of people with long-term conditions and/or life threatening illnesses are living longer than ever before, largely due to advances in medical technology. While research has begun to focus on the broader social needs of this group, it has largely treated them as homogenous in terms of other aspects of personhood or identity, including gender. Indeed, historically, disabled people have often been viewed as 'gender-less' with gender presented as a troubling and troublesome variable. It is rare for gender to feature in the management and delivery of social care services for disabled people with long term conditions. As the European Men's Health Forum states, "services have been slow to recognise the particular issues affecting men in relation to long-term health conditions".

This proposal seeks to understand more about the importance of gender and masculinity from the perspective of a group of men with long-term conditions who, at the time of their diagnosis, were probably not anticipated to live into adulthood – men with Duchenne muscular dystrophy (DMD) (see Box).

Recent research in the UK and Canada suggests that the social and psychological support needs of men with DMD are poorly served, with a continuing focus on 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. Studies have found that once further or higher education has been completed, men with DMD are likely to be living at home, with very limited day time activity or social opportunities. In particular, amid the challenges of planning for an 'unanticipated' adult life, men with DMD may well not have been supported 'to be and become men'.

All interactions between men with DMD and the range of social care professionals that they work with, provide potential opportunities (missed or taken) to include gender specific support needs. But social care staff may well not have gender on their 'radar'; may or may not have assumptions about the masculinity and

Men living with DMD

Duchenne muscular dystrophy (DMD) is an inherited neuromuscular disease which affects males (in about 1 in every 3,500 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 that may require further spinal surgery and/or assisted ventilation: curvature of the spine, respiratory difficulties and cardiac failure.

The mean age of death without specialised treatment was 19 but during recent years there have been significant improvements. In particular, teenagers who have used nocturnal home ventilation can expect to live to around 27 years and the mean age of death is continuing to rise. Many individuals are reaching stages of adulthood that were, at the time of their childhood, largely unexpected and unplanned.

'real man' status of people living with a life threatening and muscle wasting condition; may consider sexual support needs to be 'off-limits'; and may have physical and spoken interactions which emasculate.

If in 'ordinary' society, being a 'successful man' often means having a job and money, not living with parents, having sex and intimate relationships, having a car or displaying physical strength, then how do men with DMD, who face significant barriers in many aspects of life, think of their own manhood and masculinity? Do social care staff discuss and support gender related issues with men they support? How could this happen and how could it be better? These are the type of questions this study hopes to answer.

HOW WILL THE PROJECT WORK?

STAGE 1: Literature review

The team will review published work on the intersection of masculinity, men's health and disability/long term conditions. This literature review will help inform subsequent interview questions and the study's written outputs.

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STAGE 2: Fieldwork

The project will carry out 'research encounters' with 20 men with DMD aged over 18 in the south of England. Participants will include as diverse a male sample as possible, with a mix of people who live independently or with parents; are of different ages; some of whom are using self-directed support and others not; are from different ethnic backgrounds; and some with learning disabilities.

Half of these encounters will be set up and led by Dr Jon Hastie, a project team member who lives with DMD, and half by David Abbott. This will allow the project to use Conversation Analysis (CA) to look for differences in the 'gender talk' and interaction in the interviews. The project's hypothesis is that a greater level of shared identity will influence the talk and interaction in interviews undertaken by Dr Hastie as a peer researcher.

The research encounters will consist of:

Initial contact and set up: the practicalities of organising interviews may reveal something of the lived experience of the participant eg how much autonomy they have in deciding where and when to meet, participants questions about the research etc

An initial, loosely structured, face to face research interview: this will allow researchers to understand the context and background of the participants life. Interviews will explore domains associated with manhood and experiences including:

- finding activities (including work) after education/training
- views, experiences and hopes in relation to current and possible future living arrangements
- leisure, social and cultural life
- physicality and living with a changing body
- sex, sexuality and intimacy
- support from and interactions with paid professionals and/or family
- perceptions of own masculinity and gender and how others may perceive them.

Across these domains, the interviews will focus on how participants feel social care professionals could improve their practice by

being more aware of, and attuned to, gender and by including gender relevant discussion and questions in support planning, the recruitment of personal assistants, and the range of social activities where service users seek support.

Over the six months following the interview, different forms of on-going, informal contact will be maintained, where participants are willing, through Facebook and email. This will enable researchers to raise additional questions, and participants to provide information on important life changes. One aspect of this on-going communication will be to see if raising the participants' awareness of gender issues results in changes in how they think about the issues or themselves, or how they organise support or interact with staff.

STAGE 3: Analysis

Field notes about setting up interviews and data collection, interview transcripts and data collected during on-going interactions will be analysed using established qualitative thematic analysis. As well as looking for explicit references to gender, the project will be interested in 'gendered talk' where the conversation touches on concepts and attitudes linked to gender and masculinity e.g. situations in which men feel powerful/powerless and how goals and achievements are discussed and presented. A two-day roundtable discussion of the findings with a range of experts will be part of the analysis. The team will also examine the differences in the content and language of the interviews organised by the two interviewers.

Project publications

Outputs will include an accessible 'Findings' summary, event presentations and journal articles covering: the substantive issue of male gender and long-term conditions; methodological reflections on the process of Dr Hastie and Mr Abbott's work together; the conversation analysis part of the study; and the implications for social care. Newsletter and website pieces will be posted on the main Muscular Dystrophy organisations' websites, and the project may also produce good practice guide-lines aimed at adult social care staff. A short film will be produced to present and reflect on the findings.

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HOW DOES THE PROJECT FIT THE AIMS OF THE SCHOOL FOR SOCIAL CARE RESEARCH?

There is a strong policy imperative in England to deliver social care which maximises the choice and control of service users. The 2005 National Service Framework for Long Term Conditions is clear about the kinds of personalised and high quality support it wants to realise for people living with long-term conditions. However, the gender specific support needs of men with long-term conditions are rarely addressed and such men – in this study those with DMD – may be emasculated by social care processes, staff and experiences of support.

The findings will provide new evidence on the gender specific challenges and support needs faced by men with long-term conditions. This will be of direct relevance to men with long-term conditions and also important for those planning and delivering social care and for parents and family-based carers who also want to see better outcomes for the people they support. The project's range of proposed outputs will concentrate on practical and applied research messages and are intended to improve practice and outcomes.

The Research Team

The project is based on a partnership between researchers at the University of Bristol, Jon Hastie, who lives with DMD, and the Duchenne Family Support Group charity.

David Abbott is a Reader (Social Policy) at the School for Policy Studies, University of Bristol. He will manage the project overall, organise and undertake fieldwork, and lead on ethical issues, analysis and report writing. He has worked on a range of research projects relating to disabled children/young people and gay/lesbian people with learning disabilities. He was an advisor to the All Party Parliamentary Group for Muscular Dystrophy.

Dr Jon Hastie is a researcher and Involvement Officer at Brighton & Hove Federation of Disabled People. He will help draft interview materials, recruit and carry out interviews, join in the data analysis, comment on drafts of written outputs, and lead on making of the short film arising from the study. His film about living with Duchenne, *A Life Worth Living*, was released in 2012.

Dr Marcus Jepson, Research Associate at the School for Policy Studies, University of Bristol, will produce the literature review, carry out the conversational analysis, contribute to the analysis, and assist with the film and dissemination activities. His PhD was on the use of CA to explore everyday decision making between people with learning disabilities and their paid supporters.

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

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