

Social and Ethical Implications of Long-Term Ventilation for Men with Muscular Dystrophy

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PURPOSE OF THE RESEARCH

The purpose of the research was to explore the lives and identities of men living with Duchenne muscular dystrophy (DMD) who use ventilators. Ventilation represents a relatively new life-extending treatment for young men with DMD and very little is known about their experiences as adults. In total, ten men living in an urban community setting participated in the study. Each participated in an initial face-to-face interview, created a personal video “diary” and then participated in a second interview.

KEY FINDINGS

“Going Out” as a Central Activity

Day-to-day activities tended to revolve around three areas: care and maintenance of the body; solitary pursuits such as watching television, listening to music or playing video games; and excursions into the community. Getting “up and out” was of central importance to most participants, yet they spoke about how this was often difficult to accomplish. Going out required considerable planning and effort that included arranging public transport, coordinating excursions with toileting needs, dressing for the weather, and packing suctioning equipment.

It was also unsafe to go out alone because of the risk of ventilator disconnection or mucus plugging. The lack of funding for support workers to accompany ventilator users limited how far away from home some participants would venture. Two participants rarely left their homes except for medical appointments; others went out one to seven times per week on average, but far fewer times in the winter because of the cold weather.

“I don’t go out as much as I want to. Or when I go out, I have a great time, then I come back and I feel you know, blah, again. The next day I want to go out again, but I can’t. There’s no one to go with me.”

Medical Technologies

Participants spoke about positive and negative aspects of using technologies and assistive devices. Almost all of the men spoke about how they have “gotten used to” having a tracheostomy and/or using a ventilator. Fast and light wheelchairs were often a source of pride, and three participants included segments in their videos that highlighted wheelchair speed and maneuverability.

Technologies could also be the source of problems by limiting accessibility and social interaction. A number of participants spoke about the stares of strangers and/or how people “tend to see the chair first.”

“People on the street kind of freak out when they see the (ventilator) hose.”

Housing

Three participants lived in supportive housing units, five with parents, and two in a long-term care facility. Housing was a major concern. Limitations to housing options included both extensive waiting times for supportive housing and limited choice of neighbourhood and region where one resided. This had resulted in some participants having to move a significant distance away from loved ones and/or into neighbourhoods where they did not always feel safe.

“I’m very comfortable here, so it’s hard to pull away. But I think I need to pull away to truly be, like, an adult.”

Attendant Care Support

The amount of publicly funded nursing and attendant care provided to study participants living with parents ranged substantially from 7.5 hours of attendant care/week to 45 hours of nursing care/week. The reasons for this discrepancy are not clear but were not related to degree of assistance needed. Since the amount of service provided is negotiated on a case-by-case basis, the discrepancy suggests that some families may be better at navigating the system to obtain all the available services.

Living Day-to-Day

All participants, particularly those over the age of 30, tended to focus on living day-to-day with very limited reference to the future. When hopes for the future were expressed, they tended to focus on three areas: being healthy, moving out on one's own (for those who had not) and being in a committed intimate relationship.

"I don't have a plan. I just live as I go, really. I don't think too far ahead 'cause I don't know what's going to happen. If I'm still around, I'm sure I'll be all right."

Healthcare Services

Many participants discussed how healthcare services are limited for men with DMD compared with children and that existing services often did not address specific adult needs including sexual health, mental health and gastrointestinal issues. All of the men who lived on their own reported avoiding the healthcare system because of the ordeal of traveling and waiting.

"They expect us all to be gone but we're still around and we need services ... There's nothing for DMD for people my age out there really."

TEAM:

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Publications resulting from the research include:

Gibson B.E., Young N.L., Upshur, R.E.G, McKeever, P. (in press) Men on the margin: A Bourdieusian examination of living into adulthood with muscular dystrophy, *Social Science and Medicine*.

Gibson B.E., Upshur, R.E.G, Young N.L., McKeever, P. (2007). Disability, technology and place: Social and ethical implications of long-term dependency on medical devices, *Ethics, Place & Environment*. 10(1): 7-28.

Dr. Gibson is currently an Assistant Professor in the Department of Physical Therapy where she conducts research on the social and ethical dimensions of disability and rehabilitation.

RECOMMENDATIONS

The research supports a need for the following:

- ❖ Accessible multidisciplinary healthcare services.
- ❖ Research and capacity building regarding the unique healthcare needs of men with DMD.
- ❖ Engineering and design alternatives for cold weather (e.g. clothing, wheelchair design).
- ❖ Publicly-funded recreation programs.
- ❖ Equitable and appropriate amounts of attendant care services across jurisdictions.
- ❖ Expanding job descriptions of attendant care workers to include accompanying ventilator users to school or social pursuits.
- ❖ Increased availability of accessible housing options across jurisdictions.
- ❖ Accessible post-secondary education through flexible options and/or improved accommodations.
- ❖ Increased profile of men with DMD on muscular dystrophy association websites and other educational and promotional materials.
- ❖ Future-oriented care for boys with DMD. ▲