

Research Paper

# Enablers and barriers of men with Duchenne muscular dystrophy transitioning from an adult clinic within a pediatric hospital

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## Abstract

**Background:** Young men with Duchenne muscular dystrophy (DMD) live into adulthood and need specialized care. However, services for adults are fragmented. We know little about young men's experiences, their parents, and clinicians who support them as they transition to adult care.

**Objective:** To explore the enablers and barriers of clinicians, young men, and parents as they transition from an adult DMD clinic within a pediatric hospital to an adult health facility.

**Methods:** We conducted semi-structured, in-depth interviews with 16 participants (7 clinicians, 5 parents, 4 youth). We used an open-coding, thematic approach to analyze the data.

**Results:** Clinicians, youth and their parents experienced several enablers and barriers in transitioning to an adult health care center. Clinicians reported that structural factors including leadership and advocacy supported the transition. Clinicians and parents found that the availability and continuity of care both enabled and hindered the transition. Parents and youth conveyed the difficulties of adjusting to the different model of adult care and also accessing resources. All participants described how relational factors (i.e., effective communication and family involvement) enabled the transition. On an individual level, clinicians, parents and youth viewed transition readiness and other life skill supports as an enabler and a barrier to transitioning. All participants reported the difficulties of maintaining mental health for youth with DMD transitioning to adult health care.

**Conclusions:** Clinicians, youth, and parents experienced several enablers and barriers in transitioning to adult health care. Further work is needed to understand the complex transition needs of youth with DMD. © 2016 Elsevier Inc. All rights reserved.

**Keywords:** Transition; Adolescent; Rehabilitation; Muscular dystrophy; Neuromuscular

Duchenne muscular dystrophy (DMD) is a neuromuscular disease that affects one in 3600–6000 live male births.<sup>1,2</sup> The disease is characterized by progressive muscle weakness which causes loss of ambulation in the teen years along with cardiac and respiratory complications.<sup>3</sup> Although there is no cure for DMD, recent advancements in medical care have improved the life expectancy into adulthood, which has important implications for health services.<sup>3,4</sup> Young men with DMD have specialized health care needs that are unfamiliar to most adult health providers.<sup>5,6</sup> Therefore, understanding the enablers and barriers of young men,

and the clinicians' who support them within this transition, can help to inform clinical practice.

As young adults transition from pediatric to adult health services they are at risk of poor health outcomes, increased hospitalizations and social isolation.<sup>7–12</sup> Common challenges in transitioning to adult care include a lack of readiness,<sup>13</sup> adapting to new providers and service delivery models,<sup>10</sup> limited knowledge of child-onset conditions among adult health providers,<sup>14–16</sup> fragmented information, and limited specialty services.<sup>5,6,17–19</sup> A particular concern for youth with DMD is that they are preparing to transition when the progression of their disease is worsening.<sup>5</sup> Exploring this population is vital because they have different needs than other clinical groups.<sup>9</sup> Further, DMD is viewed as a pediatric disease associated with a lack of transition planning.<sup>5,9,20,21</sup> Thus, young men with DMD may not be supported in decision-making about their care.<sup>5,20,21</sup>

Disclosure: The authors report no conflicts of interest.

This study was funded by the Centre for Leadership in Child Development at Holland Bloorview Kids Rehabilitation Hospital.

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Research on DMD in Canada and the UK highlights that the social and psychological supports of men with DMD are poorly served beyond their medical needs as they transition to adulthood.<sup>11,12,20–22</sup> Abbott et al.<sup>11</sup> argue that a more personalized discussion of support needs for men with DMD is essential. Several studies have explored the intersection of gender and disability among young men with DMD as they transition to adulthood and highlight that social care did little to support their sense of masculinity.<sup>11,12,22</sup>

Parents and other informal caregivers provide critical support that help to maintain independence.<sup>23</sup> For example, Skyrme<sup>24</sup> found that youth with DMD experienced relational autonomy from supportive networks as a means of coping with the challenges related to their disability. Meanwhile, Samson's<sup>25</sup> research on the lived experiences of parents of a child with DMD reported that parents perceived their child's illness as a severe loss; a call to adapt; or rediscover the child. Indeed, it is critical to understand parent's experiences during a transition given the important role they play in their son's lives.

Our study is novel because we focused on the enablers and barriers of youth, parents, and clinicians involved in an adult DMD clinic within a pediatric hospital—offering a unique model of multi-disciplinary, and family-centered care. Further qualitative research is needed in this area with an in-depth exploration to inform DMD specific transition programs.<sup>5,12,20,21</sup> Bendixen et al.<sup>26</sup> argue that more research is required to understand the barriers and enablers affecting participation throughout the course of DMD. Further, our study also explored different perspectives: parents, youth and clinicians, whereas other studies typically focus on one perspective. Given the increasing demand to provide efficient and cost-effective patient care, gaining an understanding of the transition experiences of young men with DMD and the clinicians who support them, can help to help inform transition programming.<sup>27,28</sup>

## Methods

### Study design

Using an interpretive paradigm,<sup>29,30</sup> we conducted in-depth, semi-structured interviews<sup>31</sup> with recently transitioned young adults with DMD and/or their parents, and clinicians involved in their transition. Our objective was to explore the enablers and barriers of young men, and/or their parents who recently transitioned from an adult DMD clinic within a pediatric hospital to adult health care center, along with clinicians who support them. We conducted interviews (see [Supplementary Table 1](#) for interview guide) over the phone or in person, at the participant's choice. All clinicians and four parents were interviewed in person; the remainder (one parent, four youth) were interviewed over the phone. The research ethics board at a pediatric hospital approved this study.

### Setting

All young adults who transitioned throughout the course of this study and clients of the adult DMD clinic at a pediatric hospital, which is Canada's largest children's rehabilitation hospital and is a tertiary referral center for children with neuromuscular disorders, were invited to participate. The adult DMD clinic follows patients with DMD who are 19 years of age and older. A Registered Nurse, Pediatrician, and Respiratory Therapist see them every 4–6 months. Their cardiac, endocrinology and part of their respiratory care were transitioned to adult acute care hospitals at the age of 18 years. Prior to 19 an occupational therapist, physiotherapist, social worker and therapeutic recreation specialist also followed them.

Over the past two years, the pediatric hospital and an adult healthcare center developed connections to transition the medical care of the adult DMD patients. The adult health center is a rehabilitation facility that specializes in complex pulmonary care. At the adult health center a Nurse Practitioner, Respiriologist and Respiratory Therapist see the patients with DMD every 6–12 months for DMD and respiratory care. The respirologist prescribes the corticosteroid, Deflazacort, for their muscle strength and monitors their pulmonary function. The transition to the adult health care center started in 2014. At the time of this study 16 patients had transitioned.

### Sample and recruitment

We mailed all eligible young men and/or family caregivers (n = 16) (i.e., DMD clients who recently transitioned from the adult clinic within the pediatric hospital to adult health care center and had their first appointment), and clinicians (n = 9) involved in preparing the young men for their transition, an information letter explaining the study. After obtaining written consent we interviewed participants either over the phone or in-person at a location of their choice. We conducted interviews with a total of 16 participants (7 clinicians, 5 parents and 4 young men, aged 20–28, see [Tables 1 and 2](#) for an overview).

### Data collection and analysis

Between June–December 2015, the first author and a research assistant conducted interviews using a semi-structured guide (see [Supplementary Table 1](#)). We developed

Table 1  
Overview of clinicians.  
Clinicians<sup>a</sup>

1 Physician
2 Nurses
2 Occupational therapists
1 Life skills coach
1 Therapeutic recreation specialist

<sup>a</sup> Note: for confidentiality reasons we cannot link the individual ID for each clinician.

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