

RESEARCH

Ableist Constructions of Time? Boys and Men with Duchenne Muscular Dystrophy Managing the Uncertainty of a Shorter Life

Thomas Abrams¹, David Abbott² and Bhavnita Mistry³

¹ Queens University, CA

² University of Bristol, GB

³ Holland Bloorview Kids Rehabilitation Hospital, CA

Corresponding author: David Abbott (D.Abbott@bristol.ac.uk)

This paper draws on studies carried out in Canada (2016–2018) and the UK (2009–18) which explored the experiences of boys and men with Duchenne muscular dystrophy (DMD). Life expectancy with DMD has increased significantly and generations of men lead lives that many did not expect them to be leading. This paper searches our data to see if boys and men with DMD are supported to manage the precariousness of a life shorter than the 'norm'. Our studies had focuses on transition to adulthood, gender, social care, interactions in rehabilitation clinics, and managing conversations about death. The paper discusses how respondents framed DMD within time and the life-course. Our analysis suggests that ableist assumptions about time make the management of a challenging disease such as DMD even more challenging. We found little evidence of boys and men being helped to think through how to plan for a life expectancy that kept shifting.

Keywords: Duchenne muscular dystrophy; time; shorter lives; ableism

Introduction

Duchenne Muscular Dystrophy

DMD is an inherited neuromuscular disease which affects boys (apart from in very rare cases). 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. In countries such as Canada and the UK, the mean age of death without specialised treatment had until recently been 19. During the last few years, however, there have been significant improvements in the ways 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 (Eagle et al. 2007). Indeed, the mean age of death is likely to continue to rise as more effective spinal surgery and better detection and treatment of cardiac complications have an impact on the current generation of teenagers. Approaches to the management and treatment of DMD vary fairly widely in different countries and, for example, the use of tracheostomies at a comparably earlier age for young men with DMD in Denmark, has seen large numbers of men living into their 40s and beyond (Rodger et al. 2015).

Living with a complex, long-term health condition with a prognosis of comparatively premature death poses a range of medical, emotional and practical challenges. Boys and men living with DMD demonstrate the strengths and limitations of health, education and social care systems in the countries in which they live. Research, from a social science perspective about the experiences of boys, men and their families, suggests that there are considerable barriers to education, training, employment, accessible housing, integrated services, reliable social care support, and relationships, including romantic and sexual ones (Abbott, Jepson & Hastie 2016; Abbott et al. 2019; Gibson et al. 2007; Skyrme 2017; Yamaguchi and Suzuki 2015). These challenges often come to the fore as boys and young men make transitions between child and adult services and more broadly, at transitions over the life course relating to age, identity, and sense of self (Abbott and Carpenter 2014; Gibson et al. 2014). At the same time, the emerging population of adult men with DMD challenges quite ingrained ideas about how a life with DMD can be lived (Hastie 2012). The skills, accomplishments and aspirations of boys and men with DMD are being changed and affected by role models and counter narratives to the 'tragedy' of a life with Duchenne.

In this paper, we draw on research studies in Canada and the UK that we have completed over the last decade. We have interrogated our data to think about how the lives of boys and men with DMD speak to the theme of this special edition, namely time, the ‘cripping’ of time (McRuer 2018), and the arguably ableist construction of ideas about a ‘normal’ or ‘ordinary’ life-course and life-span. By ableism we refer to an interpersonal and institutional preference for ‘normal’ bodies, and the collective action that sustains exclusionary normalcy. By ‘crip time’, we refer to formulations of time, widely defined, that challenge such a preference, and the production of timeframes that actively contest ableism. This is more than simply a theoretical matter: the generation of men with DMD who have featured in our studies have lived with quite seismic changes in how time might be organized, managed and imagined. Most will have lived longer than expected but, alongside their families, lived with huge uncertainty about how long they will live. The considerable impact of this upon decision making across the life course (for example about getting qualifications at school, seeking a place in the labour market, or not) has, we argue, not always been helped by a one size fits all approach to organizing the lives of children and young people heading towards adulthood. Questions about how to organise a shorter life alongside great uncertainty about when that life might end are rarely rehearsed in: research; theory; interactions between boys/men and the myriad of services they interact with; conversations within families; or policy and practice relating to transition from childhood to adulthood. Questions about how to approach these issues which start from a positive framing are emerging but also rare—how can the experiences of living with a shorter life-span and a shorter amount of time from the ‘norm’ provide opportunities to organize time in interesting, novel and challenging ways? How can we see ‘crip resistance’ (McRuer 2018) in action?

Our research studies

As this paper aims to explore the multiple temporal registers to which DMD is subject, and how those overlapping temporalities contribute to exclusion, we interpret the term ‘data’ broadly. Rather than solely explore temporality from a single perspective, what people had to say about time, we explore temporality at numerous registers. First, we considered the expectations held by young men with DMD about their futures, in light of progressive neuromuscular disease. Second, we look to the institutional, developmental expectations of youth with DMD, and their transitions between socially-ordained developmental milestones. This was pursued through first-hand ethnographic observation, in the Canadian studies. Third, we reviewed interview and roundtable dialogue data with practitioners to explore how their socially organized expectations of development, transition, and decline shaped the timeframes to which DMD was subject. In this retrospective analysis of past studies, we do not aim for a single, conclusive account of DMD in time, but an open-ended exploration of how assumptions of timeliness shape, and sometimes exclude, those with DMD, their families, and their futures.

With these aims stated, we retrospectively reviewed three studies in the UK, and a three-phase study in Canada:

1. A large, UK-wide study about transition to adulthood and the experiences of service provision. The study combined a postal survey of parents plus 102 face-to-face qualitative interviews with young men with DMD, their parents, and siblings.
2. A qualitative study in England with 20 men with Duchenne muscular dystrophy exploring experiences of the organisation and delivery of social care as it pertained to their sense of being men.
3. A qualitative study in the UK with 15 men with DMD which explored what kind of conversations about death and dying men had had, as well as the nature of ones they would like to have.
4. Focusing on two clinical spaces in Ontario, Canada, the aim of these three related studies was to explore how various logics guided care practices for young people, their families and caregivers. It involved 44 ethnographic observations of young people’s clinic appointments, interviews with parents, children and youth, practitioners, clinicians, and 15 facilitated roundtable dialogues.

In this paper in which all the names of research participants have been changed, each author revisited the data we had respectively collected and analysed. In all of our studies, we observed the problematic nature of ‘normative time’ for a group of boys and men living with great uncertainty around time. The call for papers for this special issue gave us an opportunity to pay more attention to the question of time and what our participants had said—and what we had observed. We looked for examples, excerpts, and narratives which spoke to us of approaches to time, managing uncertain time, and facing and/or challenging ableist constructions of time. We shared examples of data and text with each other and discussed the theoretical and practical implications of our ideas. As outlined below, we elected to use three contexts in which to explore time: within the characterisation of time in policy and practice pertaining to the transition to adulthood; individual narratives about living with DMD and interactions within family units; and within interactions in clinical settings. These seemed to us to be fruitful and interesting sites of interest and difference. The examples from our data that we present on paper draw on our own observations, quotations from boys and young men with DMD as well as their parents, and in the Canadian study, some clinicians. We do this not to diminish the primacy of the voice of the boys and men living with DMD, but in recognition that for various reasons the lives of youth with DMD can be very enmeshed (Abbott 2012) with their parents in ways which are fairly different to non-disabled peers. Only a small minority of our cohort of boys and men with DMD lived outside of the family home and for many, parents remained primary care-givers. Children and youth who lead highly medicalised lives routinely make decisions in very

close conjunction with their parents, and we have written elsewhere about how disentangling the voices and views of youth with DMD and their parents can be problematic (Abbott and Carpenter 2015). In addition, we recognise that parents of disabled children and young people have legitimate voices, as many of them experience ableist responses to their child/family unit in their own right as, for example, Ryan & Runswick-Cole (2008) argue persuasively.

All of the studies received appropriate ethical approval. In the UK there were two particular issues in relation to ethics. One was persuading ethics committees that the work was not “so sensitive” and the participants “so vulnerable” that the work could not be carried out. Both of these assertions needed gentle challenging and seemed to us to be borne of rather disabling views about some kind of inherent vulnerability in disabled young people (see Stalker et al. 2004). The second main ethical issue in one UK study related to whether or not boys and men with DMD wanted to be interviewed together or separately from parents. Again, we have written specifically about this (Abbott 2012) but note that in some instances, interviews started at the young person’s request with their parents there, and then when a level of comfort was reached, parents would sometimes leave. Sometimes ‘whole-family’ interviews revealed particular issues (often tensions) within family dynamics which was interesting in and of itself, but also needed careful and ethical handling. Suffice to say that no one kind of interview or observation could be said to be better or ‘truer’ than another—simply different. In Canada, the concerns of the ethics committee also related to concerns that the research and researchers might upset participants. This is often an issue in social research, but we had questions about the level of paternalism at the centre of these concerns. The presumption that to be or become upset is to be avoided or managed is interesting and in some ways spoke to findings discussed below about a tendency to avoid so called difficult topics.

Theoretical Context

Kafer’s *Feminist, Queer, Crip* (2013) provides the overarching theoretical and temporal frames for our approach. Aligning queer critiques of futurity with a feminist disability studies perspective, Kafer sets the stage for temporal studies in ability. Kafer outlines how both depoliticized and politically-charged frames of disability are always already temporal. Client centred rehabilitation and the social model of disability are both implicated. Temporalities are ubiquitous, yes, but also a space and time for politics, for good or for ill. Contested imaginations of belonging, membership, past, and future are sites of inequality and ability, and it is the charge of disability studies to open spaces of dissent and access to the future for those coded without, who did not dwell within ‘our’ future generations. Of particular importance to our project is Kafer’s running critique of ‘curative time’ (p. 27) as distinct from more mundane usages of ‘cure’. One can be fully committed, suggests Kafer, to the interests of feminist disability studies and still pursue medical cures, albeit critically. One can imagine a more accessible ‘elsewhen’ (p. 3) regardless, where medicalized understandings of bodily deficiency have long been forgotten. ‘Curative time’, as such, refers not to the elapsed mechanisms only of cure, but a pervasive, institutionally cemented attitude that places disability out of time, full stop. From *Feminist, Queer, Crip*, then, we receive a chorus of activist voices, a political-relational model of disability cautious yet open to medical intervention, and a call to imagine an accessible future. Kafer’s work suggests that there is no one timeline against which our collective lives may be judged, rather a series of overlapping, contested, and potentially oppressive timeframes on which we dwell. To cultivate active futures where we can affirm lives in and through embodied difference: this is crip futurity.

To Kafer’s crippling and contestation of the not-yet, we add three already temporal literatures. First, we look to existential angles on lived time and human finitude, particularly work addressing death and dying. Phenomenology has long explored the way that human beings make sense of our finitude, set against the transcendental structures that make us what we are (Adkins 2007; Heidegger 1996). It interrogates how lived time, including our impending deaths, make us what we are. This aligns with a wealth of recent work exploring existential time in the clinical setting, how health, illness, disease, and health care relate to our timely nature. Here, Carel (2016) uses Heidegger’s philosophy of death to explore how illness brings us closer to the finitude that grounds human life, and asks how we might affirm life therein. Martiny (2015) uses qualitative research to demonstrate how continental disability challenges traditional notions of ‘illness as bodily breakdown’, emphasized by the Heideggerian tradition (see Svenaeus 2011). Congenital disability entails a gradual learning and relearning process, rather than a stable, occasionally thwarted, set of somatic skills. Both Reynolds (2017) and Titchkosky (2005) take a phenomenological approach to disability, death, and dying, arguing that phenomenological perspectives provide ammunition to combat the belief that disability equals death (or worse). Rather, it is just one of the many ways of bodying forth in the world. In looking to phenomenological work on time and temporality, we are not seeking to give a fundamental account of how all beings dwell in time—rather, we want to explore how various narratives of embodied life are made meaningful, how we emerge as temporal subjects and body-objects in those narratives, and how we might affirm the lives of young men with DMD within them (Akrich and Pasveer 2004). We are not looking for universal human attributes, but rather the timely narratives whereby we interpret embodied life as it is.

Secondly, we turn to affect theory, highlighting the distributed, assembled, and emergent nature of disability, temporality, and health care (Fox and Alldred 2015; Puar 2009; Feely 2019). Here, disability and impairment, like any other bodily form, are the outcome of multiple connectivities, making and remaking worldly entities (Gibson 2006). It is not just disability and impairment themselves that are constituted by connectivities, but the care trajectories applied to disabled-and-impaired bodies, unfolding in the care home, the clinical space, and the private dwelling. In each of these spaces, disability is an institutionally organized outcome, with various expectations, contestations, and emotional attachments that make it what it is. Whereas the phenomenological work allows us to explore the narratives through

which we interpret our human *situation*, affect theory allows us *to situate* those meaningful narratives within the connectivities that enable them. Bodies, emotions, and institutions all intertwine to constitute disability, disablement, ability, and agency throughout multiple spatial and temporal registers. Affect theory supplements phenomenology's meaningful enterprise with the institutional entanglements that allow its objects of inquiry to emerge in the first place.

Thirdly, and drawing from the abstract theorizations charted above, theoretically-rich qualitative policy work has documented how disabled persons are subject to multiple registers of time and temporality throughout their life courses. Kelly (2018) explores the imagined futures of Canadian youth with disabilities, emerging in interactions with service organizations. Here, multiple temporal registers intertwined, whereby daily tasks, institutional timeframes, and future expectations led youth to feel out of time, but also presented opportunities for affirmation of bodily difference. Similarly, Moola and Norman (2011) chart how youth with cystic fibrosis and those with congenital heart disease challenge and defy normative expectations of "able-bodied time" (p. 849), questioning ubiquitous assumptions of life and life course in existing health care research and practice. Finally, Gibson et al. (2014) follow how men with muscular dystrophy in Canada navigate socially organized transition schedules (school – college – work = successful transition) and perform masculine identities within them (p. 101). They found "narratives of non-difference" prevailed (p. 99), whereby participants assumed and performed "normal" men's identities, while taking impairment-specific detours from the normative temporal paths.

In the following sections, our aim is to provide a theoretically-rich qualitative inquiry into disability and temporalities, at three interacting registers: a) individual narratives of DMD in time; b) institutional analysis, exploring how temporalities are put to work at the institutional level; c) temporalities, plural, unfolding in the rehabilitation clinic. This list is not exhaustive, nor does one single timeframe exist in isolation. Their sum allows us to chart stories of how young people, their parents, practitioners, and policy-makers accept, reject, or remodel disability as a time-bound and timely outcome. To borrow some of Kafer's words (2013: 46), "we must explore [DMD] in time".

Exploring DMD in time: The bureaucratic organisation and policing of time in transition processes, policy and practice

Transition to adulthood brings time into sharp focus for disabled young people and their families in two main ways. Firstly, the transition from one set of services to another: health clinics, social work/care services, rehabilitation services, and educational settings. More than 30 years of research has highlighted the very poor experiences of young disabled people and their families as they make these transitions (Beresford 2004; Morris 2002). Secondly, transition to adulthood encompasses a much broader set of non-linear changes marking emerging identity from childhood to young adulthood. Societal expectation of this part of the life-course is populated with widely accepted and expected goals: autonomy, independence, labour market participation, responsibility for health care management and greater decision making, an emerging sexual identity, and so on (Jones 2002). Others have written about how the uncritical pursuit of a normative or ableist approach to what 'good adulthood' looks like can marginalise and disable young disabled people (Hamdani, Mistry & Gibson 2015; Tisdall 2001).

In both Canada and the UK there have been rafts of law, policy, good practice guidelines, toolkits, research and so on, all aimed at 'cracking' transition. Their primary focus has been on smoothing transitions between child and young adult/adult services and reducing inequalities of outcome as compared to non-disabled peers. However, these policies, rhetorically intent on maximising the life chances of disabled young people emerging from childhood, sit alongside austerity policies which have, in the UK and Canada, reduced and removed social protection for disabled people, and focused primarily on welfare sanction as opposed to welfare support (Goodley, Lawthom, & Runswick-Cole 2014; Prince 2012). McRuer (2018: 101) argues that austerity, '...generates extravagant abjection, literally wounding bodies and minds...' and McLaughlin (2017: 244) points to the emphasis on the necessity to have achieved both autonomy and a competent and productive body to avoid stigma and labelling.

For our study participants, 'transition' represented both a lot and a little; a lot in practical terms, as in big changes in service provision, and in psychological terms—excitement and fear about getting older, as well as a lot of time invested in meetings, paperwork and bureaucracy. But it could also represent very little good use of time or useful benefit, as often meaningless processes around transition were embarked upon with varying degrees of enthusiasm. In the midst of this future time-oriented part of the life-course, our data suggests several sometimes seemingly contradictory approaches to time. On the one hand, a slavish attention to processes which focus on planning and organising time for a normative lifespan—rarely is consideration given to how to organise 'less' time; on the other hand, the emphasis on bureaucratic process serves to waste (arguably precious) time. What we mean is encapsulated by these two excerpts, the first from a 15 year old boy:

What is transition anyway? I don't have a clue. They deal with adults crappy compared to children. You hear these stories that you don't get things as quickly.

Mum: She [social worker] came to the house to do his transition when he was 18...

Interviewer: What did that actually mean—'coming to do his transition'?

Dad: Is it to make sure you don't just disappear from the books or something? I don't know.

Mum: It took 3 hours and she never got back to me.

Hence, we see the disposability of youth being failed and failing in and at time (Gibson, Zitzelsberger & McKeever 2009). This can be quite explicit as in these excerpts from our data:

Young man: 'It does seem to be that before you're sixteen there is a plan; this happens then that happens, and it's smooth. Then you get to a certain age and no one's thought about what happens next. It's like, 'We've done our job now, it doesn't really matter what happens next just find out for yourself.'

Mother: '[Son] will be twenty-five this Christmas and it's as if some people think, 'Oh you're still around, you shouldn't be, we don't know what to do with you'.

One mother said that she had been told that her son was not a sufficiently high enough priority for hydrotherapy. She felt that this was giving a message that his shorter life meant that he was not 'worth it':

'I asked for hydrotherapy and the local physiotherapist actually said, "There's a waiting list and some of the children on it will actually go into adulthood so we have to make provision for them". So, I said, "With adequate physio there's no reason why my son can't make it into adulthood." To me it just said, 'I don't have enough money, I'm prioritising the ones that will make it into adulthood and sorry, you're off the end and if he dies well, it doesn't look too bad, because we're all expecting that anyway.'

Processes supposed to help with major milestones towards adulthood, such as labour market participation, were rarely adapted for the lives of the men which were highly likely to be shorter. However, some men put up rather feisty counter-narratives to widely accepted transition goals. Some men opposed the idea that they should work at all. In this interview, the young man was at home having finished work and college and not doing very much during the day. His mother responded to the topic of employment:

Mother: A work environment or something would be good.

Young man: I wouldn't want a work environment. I've never thought about working before.

Mother: It's like, would he be able to do things?

Young man: There's no jobs I like anyway.

Mother: Well there is going to be a new supermarket...

Young man: I'd get bored too easily. There wouldn't be much for me to do. It'd be tiring.

Exploring DMD in Time: Individual

At the individual level, *crip time* manifests in the existential and developmental frameworks into which youth are thrown. Particularly important here are discussions of life-course planning and discussions of death. In both cases, youth with DMD challenged, and were challenged by, culturally-prescribed timeframes. Uncertainty was rife over matters both 'medical' and 'social'. In each case, however, we also found that friction managed or challenged—overcome or otherwise.

Life-course planning

Data from both Canada and the U.K. highlighted the friction between typical developmental paths that non-disabled youth would take, and those found within the DMD community. In our Canadian data, for instance, we found many participants reflected on the choices that they would need to make for education and career paths that would deviate from the typical education–work transition. Sahil (17), for example, was interested in pursuing a university-level education in child services. He expressed significant worry that he would be mobile enough to care for children in the future. Without a comprehensive strategy to address these concerns, the investment in a four-year degree came into serious question. What would be an unthought career trajectory for the typically-embodied 17-year-old was far more complicated for Sahil.

Uncertainty does not, however, mean impossibility. In both Canada and the U.K., we found that much career uncertainty had to do with inadequate supports offered to youth with DMD, rather than anticipated bodily changes. In Canada, Ron (15) found that he was unable to properly utilize career support services early enough, with the extra time needed to secure summer work—a culturally-ordained stepping stone for post-education employment. In the U.K., we saw similar problems with supports. Youth were either given a job opportunity deemed suitable for 'the disabled'—gardening, a charity shop, or factory work, noted two respondents—which they could take or leave, or nothing at all. Many chose the latter. They did not do it because they were lacking in potential or were unable to complete the work to meet required qualifications. Given the infrastructure and time-investment needed to have their potential realised and considering the known life-span of youth with DMD, potentially unused qualification had a high price tag. One father in the U.K. presented his son's choice accordingly:

'He sees school as somewhere to do social events rather than learn. He's very much of the view that he's never going to get a job, "...cos I'm too physically disabled". I have to agree with him. This is why originally, like when he was 14 or 15, he wasn't looking in the long term for qualifications. 'Cos he's saying, "Well it's a waste of time, I'm not going to be around, you know. And then if I snuff it the next year it's a waste of my time." You know he

sees it as a waste of time, like he just wants to have as much fun as he can while he's still young. You can see his point of view.'

End-of-life discussions

Just as expectations about life-course planning were significant for youth with DMD and their families, discussions of death also introduced friction between multiple temporal registers, and offered examples of resistance on behalf of disabled youth and their allies. In both data-sets, young people demonstrated that they were very much willing to address questions of death and decline head-on, but often were without an ear willing to entertain the discussion. In one of the UK studies, a man with DMD reflected on the limits of diagnostic certainty in end of life discussions.

'Doctors say a lot when you're diagnosed—you won't be able to walk, you'll have to go into a wheelchair—then they suddenly stop when you come to death. It's odd really because they're leading you to the door of the conversation but they're keeping it closed which makes it more scary really. If a doctor can't talk about it and you don't have a close relationship with your parents when it comes to these types of issues, then who you gonna call?'

Even in cases where close relationships with parents existed, youth expressed frustration with a lack of dialogue. Asking his mother about typical lifespan DMD, one UK respondent felt that the suggestion of 'being positive' was used not to note the good parts of life, but simply to close-down discussions of death; 'I came home and I spoke to my mum. I asked her if I had a short life. She said yes but they didn't want me to think about dying, *they just wanted me to be positive about life [our emphasis]*'.

In a Canadian example, Kyle (10) found it difficult to ask questions about death with clinical practitioners in front of his parents. "For some reason, I don't think I'll make it to 18", he noted to the clinic's pediatrician, his parents' eyes quickly welling up. Tears aside, the doctor gave him the answers he was looking for. "I think you will," she said, explaining the likely life course in terms he could understand. Despite resistance—less than many parents we observed and interviewed, it should be noted—the friction was overcome.

Despite normative timeframes that would place them 'out of time', youth with DMD and their families showed a willingness to re-enter timeframes on their own terms. Youth actively worked to overcome uncertainty that would come up in life-planning, particularly in terms of employment and 'prospects for disabled people'. In several cases, that meant no prospects at all. However, we would note that on some occasions, disabled persons placed themselves out of time, because of the work needed to acquire membership in a particular activity. Work placement or skills development was often very much a waste of time. Here inaction is far more an act of resistance than begrudging recruitment. In the case of end of life planning, this meant young people were asking questions about a timeline without them, even in their future absence. Out of time, perhaps, but on their own terms.

Exploring DMD in time: In the clinic

Conversations in the clinic about time and change tended to be organised around milestones in how the body functioned—when to start steroid use, when to introduce the wheelchair when mobility became a concern, when to use the Bipap machine when breathing became laboured, when to attend clinic appointments. These conversations began at diagnosis and continued on the child's life journey in the clinical space. Finding time to speak to the more complicated topics (psychosocial) was difficult, for both families and the clinical team. Coming to clinic was also a pause for what happened next in the diagnosis: was a new treatment or therapy required if decline was noted? Yet at each of these stages, children/youth and their families could be seen at times to break from the trajectory that was being suggested to them and try to forge their own path. The following section describes how children and their families experienced and negotiated time in clinic.

Organising and prioritising time in clinic

Families were asked by clinicians about their priorities each time they attended clinic. Priorities centered around body and equipment functioning – strength that might be lost or a wheelchair that needed attention. Families rarely brought up the more complicated aspects of living with DMD, such as physical decline or maintaining relationships. Room was not explicitly made for these challenging issues. When Sahil (aged 17) was asked if the topic of dating was ever brought up in clinic, he said it was not, but wanted room to discuss it.

Sahil: ... I wouldn't just bring it up. Maybe if they would ask, then I would talk about it.

Interviewer: Do you want them to ask about that? ...You do want them to ask?

Sahil: Yeah...

Interviewer: ...It is because you don't bring it up? Or is it because they don't bring it up?

Sahil: Well, we both don't bring it up.... if it's like so much stuff we already talked about, I just don't want to talk about anything more.

Our observational data showed that children/youth learned from an early age how the clinic worked. They attended for 2.5 or more hours every 3 to 4 months, depending on required assessments and prescribed treatments. At times, it was also reinforced by parents or other caregivers that they had to stay for the full time and listen to what the clinicians were telling them, particularly authority figures such as the doctor. This was said to be important to their health and wellbeing as a child with DMD. Yet, children and youth found interesting ways to subtly challenge/push back against the time within the clinic space.

Amaan (aged 11) came to the appointment with his mother. While observing Amaan's appointment, he would often look at the clock on the wall, keeping close track of the time. With the arrival of each clinician, time ticked away, leaving Amaan more and more anxious about when the appointment would end so that he could get back to school in time for recess. The clinic's time and the clinician's agenda were superseding Amaan's wishes.

Amaan asked mom to wheel him to the room. He then whispered something to mom. She, in joking tone, asked [respiratory clinician] to tell Amaan not to rush. [Respiratory clinician] said, "But you just got here!" [observation notes]

Time moved slower and slower for Amaan as his mother continued to ask questions and engage with the clinicians about her child's health. Yet Amaan remained firm with his mother during the quiet moments between each clinician's visit, vocalizing his frustration several times, "Let's go, let's go, let's go!" It was not until later in the appointment, when the physician and an occupational therapist recognized Amaan's eagerness to leave to return to school to be with his friends, that Amaan seemed less anxious. Clinical assessments were put aside to respect and acknowledge his wishes:

Dr. asked Amaan if he was going back to school. He said yes and explained that he wanted to get back in time for recess. Dr. laughed and said, "Of course. That's the most important part!" Amaan smiled and nodded, in a way that suggested he was relieved that someone finally understood his need to leave. [Occupational therapist] got right down to business as she pulled the chair close to both mom and Amaan, "Okay, I heard you're in a hurry. Okay, so we'll be fast!" [observation notes]

Families also pushed back against difficult appointment schedules. Families who lived far away or who were often at the facility had their regularly scheduled clinic visits changed to provide families with a break. Billy's family lived quite far from the facility. His mother and father were always anxious about attending clinic, still grieving the diagnosis, and had delayed their current appointment by about 9 months. The family and clinicians discussed stretching out their appointments to be at home as a family. The clinical team supported this decision. The discussion also touched on a future time when Billy might be able to make his own choices about clinic:

Mom then asked if there was an age where Billy would begin to say that he did not want to come to appointments. [Social worker] smiled and said that it does happen, but it depends on each family on how they want to deal with that. [Social worker] said that sometimes the family will tell the team, "We need a break!" Dad laughed and said, "We out!" [observation notes]

Clinic taking up family time

Clinic appointments transcended the clinical space. Common among the accounts were families describing travelling from far to come to the facility. A significant amount of work went in to preparing for the travel to the facility. Families had to factor in traffic times, meals, charged electronic devices, and the exhaustion of the long day on their bodies. Hayden (aged 8) came to his appointment with his dad. The family lived over an hour from the facility. With traffic, the family's travel time could be more than double. It made for a long day for the family:

I asked dad how long their appointments were, and he said 3 to 5 hours, adding with a laugh, "It's a long day for the driver." Hayden smiled and nodded, continuing to bop around on the bed as he ate. [observation notes]

In the UK, it was common for boys and men to see many different clinicians in different settings, unless they were part of one of the few multi-disciplinary and all-age specialist centres. Having so many different appointments could become akin to a full-time occupation. Whilst many of the men described childhood passivity in relation to going where they were told to go by their parents, some were questioning what they saw to be the needless over-medicalisation of their adult lives, especially in the context of time and energy being short and perhaps precious. One young man faced the prospect of seeing three different consultants at different times and decided that he was not going to:

'I don't want to see lots of different doctors all the time because there isn't much they can do for me at this stage with my condition. If they can't do anything, the last thing I want is to see a load of doctors who depress me with bad news!'

In a different interview with a mother and son, there was more explicit discussion about the waste of time associated with seemingly pointless medical interactions:

Young man: It's a waste of time...

Mother: ...when you were young you thought you were going to the doctors to get better. But then as time went on you realized things aren't going to get better. What's the motivation for going if you're just told how much worse you are?

Young man: He could talk to us over the phone instead of going all that way. He only spends 10 minutes with us when we go anyway!

Discussion and Conclusions

Our paper suggests that the conceptualisation and organisation of time can be a significant issue for boys and men living with DMD as well as their families. Not every day; 'ordinary' family life continues apace. But, with some exceptions, what we do not detect is a bigger project to help boys and men think about time on their own terms, and which takes account of the fact that time is uncertain. Whilst we see moments in clinical interactions where professionals acknowledge that their priorities may be different to the boys and men, we still see a deep reticence to address and talk about (in policy, practice, and research) the challenges *and inherent value* of a shorter lifespan. We see the emergence of these discussions in research with young disabled women in important, co-produced research led by Liddiard and colleagues (Liddiard et al. 2018). In this study and its associated blogs (Whitney 2018), we hear from young women with 'life-limiting' conditions who say that no one has ever asked them the 'big questions' about what it is *like*—emotionally, physically, and psychologically—to live with a likely shorter lifespan. These discussions are overdue in research and in interactions with health and social care practitioners (Gibson, Zitzelsberger, & McKeever 2009). We require new narratives about shorter lives and should start by foregrounding the voices of those with lived experience who continue to challenge tragedy narratives. That said, in this space we might want to avoid replacing one orthodoxy with another and not shy away from feelings of loss or sadness.

Revisiting our past work in light of the theoretical themes pervading this issue, we found multiple temporal registers implicated in living with DMD. The logic of developmentalism, found in both routine clinical practice and policy-work aimed at 'solving disability', is but one way that we find DMD in time (Hamdani, Mistry & Gibson 2015). Life with DMD is timely not solely because people will become more disabled and die, nor because there is a policy cliff that people will fall off of once they are no longer children. We found 'timeliness' in the ways that young men engaged with their finitude head-on, in discussions of death and dying. We found 'untimeliness' in the ways that social services saw young people as an unworthy investment, with a 'lucky' few placed in a just-temporary job for their just-temporary adulthood. Finally, we found narratives of 'time-wasting' in the ways that clinical visits were tailored to illness progression, and not the needs and desires of young people and their families with DMD, seeking accessible futures (Abbott et al. 2017; Setchell et al. 2019). In each of these ways, time means more than simply duration or decline, but a temporal way of life—one that can be acknowledged or ignored depending at the expense of individual worth (Abrams and Setchell 2018). We are some way off from the task set by Moola and Norman (2011: 849):

...constructions of developmental time need to be challenged in research and clinical practice, as one of the deeply buried ideological assumptions of our time. We would extend this claim from policy and clinical spaces to the philosophical exploration of lifetime itself. The presumed subject of much philosophical discourse possesses a 'normal' life trajectory, free of chronic illness, possesses a care-free childhood, and faces death looking back at a fully developed life. A life can be lived and shared without these things. As in all things, with help we can flourish regardless and philosophy should be mindful of this.

These reflections have practical implications for policy and practice. Our data about so-called 'difficult conversations' help make an unassailable case for clinicians' skilling up their confidence and approach to offering proactive cues that very few topics, if any, are off-limits. Transition protocols should take account of differing lifespans and suggest ways in which young people with shorter lives could be helped to plan goals which are as similar or different to other peers as they might wish. The myriad of services that attend to youth with DMD and their families might consider how the organisation of contact with families might best be streamlined to avoid wasting time, energy, and resource. Spaces and places where families can see several key professionals in one place and over one period of time would likely go a long way towards this. Promoting and supporting the autonomy and confidence of young men with DMD to, over time, lead their own interactions with services (with whatever degree of support required) may also be helped by the emergence of user-led organisations for men with DMD, the visibility of adult role models, and a challenge to the idea of DMD as a disease of childhood.

Theorizing the multiple timeframes invited by DMD, at the individual, familial, and institutional levels, is not only to tell a fatalistic story. Indeed, looking to these overlapping modes is a way to invert fatalistic logics that see life with chronic or progressive disability only as a life too short. Seeing DMD as a progression into nothingness—and only a

progression into nothingness—casts off the eventful way that people with DMD make time in the everyday world. This comes in asking questions about finitude (like anyone else), in forming groups around shared concerns of justice and equity (like anyone else), and navigating the common, future oriented world, barriers notwithstanding (unlike anyone else). By reflecting on the many ways in which DMD is made futural, and the ways it is denied a future, we can do the same type of social justice work that disability studies have been doing since their outset. We can make futures accessible by making them visible, particularly to the single-axis trajectory suggested by developmentalist discourses. Documenting and theorizing the multiple temporal pathways life with DMD will take, however, show us that disability identity and activism is but one type of futurity desired and realized by our informants; accessible futures take many forms. The point is to open them, wherever they might lead.

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Competing Interests

The authors have no competing interests to declare.

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