Men on the margin: A Bourdieusian examination of living into adulthood with muscular dystrophy

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Abstract

Men with Duchenne muscular dystrophy (DMD) are part of a growing population of community-dwelling persons dependent on life support technologies. This Canadian study drew from Bourdieu’s critical social theory to explore the identities and social positionings of 10 men with DMD in relation to dominant discourses of disability, masculinity and technology. Semi-structured interviews with participants and participant-generated video diaries revealed that these men were materially, socially and symbolically marginalized through inaccessible built environments, social arrangements that limited their engagement in community life, and the multiple ways that their bodies were negatively marked across social space. Furthermore, their marginalization had been embodied through processes of socialization and internalization of subordinate social positionings. While the men created positive personal spaces for recognition and success, their achievements were severely circumscribed by significant social inequities.

Keywords: Canada; Disability; Technology; Identity; Masculinity; Bourdieu; Men; Muscular dystrophy

Introduction

Advancements in life sustaining and assistive technologies such as mechanical ventilators and power wheelchairs have altered the life expectancy of people with severe disabling conditions and the kinds of lives that are possible. Men with Duchenne muscular dystrophy (DMD) are part of this relatively new but growing population. DMD is a genetic disorder affecting male children characterized by a progressive weakening of skeletal muscle leading to loss of physical abilities and eventual respiratory failure. Only in the last 15 years with the availability of home mechanical ventilation and improved medical therapy, have boys with DMD been able to survive past childhood—into their thirties and potentially longer (Yasuma, 1996). Many young men with DMD live in the community alone or with their families. By the time they reach adulthood, they are highly reliant on personal care attendants and assistive technologies for most activities of daily living.
Very little research has considered what life is like for persons who are profoundly reliant on multiple medical technologies and human supportive care. Drawing from Bourdieu’s critical social theory, we explored the identities and social positionings of men with DMD by examining how they respond to dominant discourses of disability, masculinity, and assistive technologies. Our objective was to illuminate the extent to which current social arrangements not only limited the social participation of men with DMD, but structured their personal identities. Before discussing the study details, we first provide a brief overview of Bourdieu’s main ideas and locate his work within current approaches to conceptualizing disablement.

A Bourdieusian approach

In describing disabled bodies as bearers of value, Edwards and Imrie (2003) draw on Bourdieu’s key concepts to interrogate the interrelationships among disabled bodies, and broader socio-cultural values and practices. Like others (Hughes & Paterson, 1997; Thomas, 1999; Wendell, 2001; Williams, 1999), they have responded to recent critiques of the “social model” of disability that has dominated disability research and activism for the last 30 years. The social model emerged in the 1970s to challenge biomedical understandings of disability as an individual problem resulting from a biological impairment (Barnes, 1996; Oliver, 1996). The basic premise of the social model is that disability is the outcome of exclusionary social and material arrangements. In focusing on the social production of disability, the model has contributed to shifting policy debates and research agendas from the medical to social and political fields (Silvers, Wasserman & Mahowald, 1998, pp. 74–76). Recent critiques, however, argue that the social model—or at least work advanced in its name—focuses too heavily on social and material barriers with little consideration of the cultural and experiential aspects of disability and the significance of physical impairment in people’s lives (Thomas, 1999, pp. 24–25). In response, models of disability that integrate the social with the personal by focusing on interrelationships between bodies and socio-cultural contexts have emerged (Hughes & Paterson, 1997; Turner, 2001; Williams, 1999). Edwards and Imrie (2003) suggest that Bourdieu’s conceptualization of the correspondence between embodied dispositions and social location is a potentially fruitful approach to circumventing the dualistic characterizations of disability as either a product of a biological deficiency or as the result of socio-political disadvantage.

Bourdieu’s work is concerned with understanding collective and individual human practices. “Practices” refer to observable behaviours, beliefs, strategies, thoughts, attitudes and tastes. He contends that even the mundane practices of individuals and groups exhibit a practical logic that is neither the expression of rational calculation nor the result of external structural determinations (Bourdieu, 1980, p. 50). Instead he posits an “economy of practice” that integrates personal and social factors in a dialectical relationship. In Bourdieu’s formulation, human action is neither an unmediated response to external social factors nor an outcome of internal reflection, but a dialectical synthesis of the two.

For Bourdieu, all human practices reproduce or transform the hierarchical distinctions made amongst groups and individuals. He described how social processes place individuals and groups within competitive hierarchies where they struggle for relative status, and how these struggles reproduce the positioning of dominant and dominated groups. Persons are said to acquire a pre-reflective comprehension of the social world and their positionings in it by incorporating the structures of the social environments in which they act and are acted upon since birth (Bourdieu & Wacquant, 1992, pp. 120–121). Through repeated exposure to particular social environments, persons develop a set of dispositions attuned to regularities in their familiar world. This acquired set of dispositions, reflecting the social conditions of each person’s existence, is termed habitus.

The habitus inclines persons towards particular, predictable behaviours, feelings and attitudes in given contexts (Bourdieu, 1990, pp. 7–10). These are neither reflective nor automatic, but result from the interplay between individual decision-making and relevant social structures. Similarly situated persons—that is, those who share a set of economic, social and cultural conditions—will share dispositions or a “group habitus” (Bourdieu, 1980, p. 60). The habitus acts as a kind of repository of accumulated experience that precedes individuals. Habitus thus becomes instrumental for the reproduction of the social order over time, ensuring its tenacity precisely because it is experienced as natural rather than constructed.
Human practices, for Bourdieu, are the result of the interaction of the habitus in a given field. Fields are relatively autonomous social microcosms such as the family, the health care system or the education system that have their own set of tacit rules and understandings. Fields are characterized by the juxtaposition of social positions, that is, the mutual exclusion or distinction of persons or groups from each other (Bourdieu, 1997, p. 134). A person’s (or group’s) position in a field is determined by the amount and type of field-specific capital at his or her disposal. Capital is any resource that is acknowledged as valuable within a field. Fields are sites of struggle where possession of capital determines one’s position or status.

For persons with physical differences, physical capital, that is, physical attributes and abilities judged positively or negatively, can hold particular relevance across fields. Like any type of capital, the symbolic meaning attached to it has an exchange value that contributes to one’s social position (Shilling, 1993, p. 127). Edwards and Imrie (2003) developed this strand of Bourdieu’s work to explore how disabled people’s bodies are often perceived as deviant from a prescribed set of social norms or seen as symbolic “others”. They suggest that associated conditions of social inequality are related to the processes by which dominant bodily forms monopolize available social, cultural and economic capital across different social fields. These considerations of the materiality of the body and how it is signified augment Bourdieu’s sociology of practice which, as Shilling (1993, p. 148) has argued, contains an underdeveloped view of the physical dimensions of embodiment.

Our study builds on these ideas to consider the interplay of disabilities, bodies, medical technologies and socio-material environments in mediating the identities of men with DMD. Identities were conceptualized as dynamic practices oriented to maintaining or transforming one’s social positionings. Positionings refer to both how one is categorized and labelled by others and the practices of individuals to achieve, maintain or resist these categorizations. Identity was viewed as an expression of the habitus, integrating individuals’ experiences of social identification with their perceptions of personal identity. Bourdieu claimed that the classifications that identify persons as belonging to social categories are the object of both “mental” representations, that is, persons’ perceptions and presuppositions, and “objective” representations such as official naming/classifying (Bourdieu, 1991, p. 220). Both types of representations are potential stakes in a struggle for position in social space. Our conceptualization of “identities” is thus equated to one’s social locations—both how one is recognized as belonging to social groups/categories, and into what groups one claims or resists membership. Identities are plural because persons do not possess a single fixed identity nor is there one “disability identity” but multiple identities that traverse categories and fields. Though the social locations of individuals and groups are relatively stable and predictable, they are not static or given but rather are continually negotiated, produced and reproduced (Bourdieu, 1991, p. 227).

Our study focused on disabilities and masculinities and the effects of medical devices on how the body is socially identified and experienced. The purpose of the study was to explore the identities and social positionings of men with DMD by examining how they respond to dominant discourses of disability, masculinity, and medical/assistive technologies. Discourse used in this context referred to the ways of conceptualizing, speaking about and representing certain parts or aspects of the (physical, social, psychological) world (Fairclough, 2005; Robertson, 1998). Persons were viewed as both products of and producers of discourses in their day-to-day interactions. Our aim was to examine how participants drew on different discourses to make sense of the social world and position themselves within the social order. For example we wanted to observe how participants accommodated and/or resisted dominant discourses that equate masculinity with strength and independence (Connell, 1995), or pervasive representations of disabled people as weak and pitiable (Gerschick & Miller, 1995).

Consistent with our Bourdieusian framework, masculinities and disability identities were conceptualized as relational, plural and situated practices aimed at improving or maintaining one’s social position. In Bourdieu’s formulation, the body is a sight of the exercise of social power where the receiver recognizes the categories of perception and appreciation as they apply to one’s own form (Bourdieu, 1984, p. 207). Bodies coupled with medical devices do not comply with pervasive standards of legitimate bodies nor do they meet pervasive stereotypical notions of masculinity. Bourdieu’s sociology specified to the case of disabled and gendered techno-bodies provided a
conceptual grounding for further exploration of these notions.

The study

Ten ethnographic case studies of men with DMD living in a community urban setting in Canada were conducted. To be included participants had to be a minimum of 18 years old, dependent on ventilation for all or part of the day, speak English, and be able to understand the interview questions and purpose of the research. We used a comprehensive sampling strategy wherein an effort was made to identify everyone who met the inclusion criteria and invite them to take part in the study. Initial contact with participants was made by four collaborators that included a nurse coordinator at the regional paediatric neuromuscular clinic, an outpatient respiratory service coordinator at the regional adult facility, the coordinator of Citizens for Independence in Living and Breathing (a now disbanded national consumer group) and the director of a large local supportive housing organization. Fourteen individuals were identified and 10 consented to participate. Ethics approval was obtained from the local university’s research ethics board.

A case study of each participant was conducted that included an initial in-depth interview at the participant’s place of residence, a participant-generated personal video account and a second interview to explore the video creation and content. For the video accounts, each participant was provided with a hands-free video camera and asked to record anything over the course of one week that he believed would reveal his life and “who he is”. All interviews were audiotaped and transcribed. The audio portions of the videotapes were transcribed and a textual log was created for each tape that described the setting, persons present, and interactions, as well as initial analytic impressions (Rich, Lamola, Gordan, & Chalfen, 2000). All textual data from interviews and videotapes were imported into the NVivo 2.0 qualitative software program (NVivo, 2002).

The data analysis was theoretically driven using the techniques described by Miles and Huberman (1994). Briefly, all data for each case were analysed using a flexible coding system and a set of guiding questions derived from and consistent with the research purpose and the Bourdieusian conceptual framework. The video accounts were further analysed using the “Movie Method”, a technique designed for the study that examines the process of video creation using a set of guiding questions that has been described previously (Gibson, 2005).

Results and interpretations

The 10 participants ranged in age from 22 to 36 years with an average age of 30 years. Five lived in private homes with their parents, three in supportive housing apartments with on-site attendant care services and two in a long-term care facility. All were born in Canada and three had parents who had emigrated from another country. The men had been using ventilators from 2 to 16 years. Seven used ventilation 24 h a day delivered via tracheostomy. Of the three who used ventilation part time (for night, naps, and as needed), two had tracheostomies and one used a non-invasive facemask. Nine men used power wheelchairs for independent mobility while one used a manual chair and required human assistance. All relied on other medical and assistive technologies including environmental control units, gastronomy tubes, ceiling lifts and urinary catheters. All received attendant care services ranging from 2 to 9 h per day and required 24-h “on-call” assistance either from family or paid caregivers.

Interviews ranged in length from approximately 1 to 3 h and videotapes from 13 to 70 min. The data set included 29.5 h of audiotape data and 5.7 h of videotape data. Although the video data were integral to the analysis, because of space and format constraints we have used interview quotations more frequently in order to succinctly represent the data. A more detailed description of the video content and analysis has been published elsewhere (Gibson, 2005).

Although the participants differed in socio-economic status, living circumstances and personal histories, they shared common experiences related to living with DMD. Day-to-day life tended to revolve around three sets of activities: care and maintenance of the body; solitary pursuits such as watching television, listening to music or playing video games; and community excursions. This latter activity, “going out”, was a central occupation of their day-to-day lives. Although two men rarely left their homes, the remainder generally went out between 2 and 5 times per week in fair weather.

The importance of being “out of the house” was reflected in five participants’ video accounts that included scenes depicting meeting a friend at the
local mall, walking a dog, visiting extended family, and moving about the neighbourhood. Harry (all names are pseudonyms), who lived with his parents, included a narrated segment about his daily neighbourhood walk that emphasized the importance of being on his own for a few minutes a day:

I normally go on the same short route this way. I just call it “the usual” so people know where I am if I don’t come back in 15 min…. Nice that I could do this. Get a little bit of time alone, without other people to bother me. Gives me a taste of independence. For a little while I make my own decisions. I’m free to go where I want to go.

For all of the men going out required considerable planning and effort including coordinating with meals and toileting needs, dressing for the weather, ensuring batteries are sufficiently charged and packing suctioning equipment.

Excursions also carried a set of barriers and risks including potentially life-threatening mucous plugging or ventilator disconnection that limited how far and how frequently participants travelled from home. Participants had varying approaches to these risks—from never going out alone, to staying close to home when unaccompanied, to accepting the risks and travelling farther afield. The four men that did venture out on their own discussed tradeoffs between being safe and being able to access the community independently and, as Robert puts it, “living the little bit of life that you have”.

Amongst the participants there emerged a distinct subgroup of four men (Alex, Zack, Brian and Mike) that, borrowing a term used by one of them, we will refer to as “DMD boys”. These men had lived in the same paediatric long-term care facility for several years as adolescents (although not all at the same time). Although each was unique, they shared a particular set of values and priorities. They were more likely to express anger regarding their impairments and social disadvantages, and displayed a kind of street smarts regarding living with DMD and working the system to their advantage. They also tended to have more experience with drugs and alcohol, and were generally more assertive than others. Zack described the experience of living in the facility like this:

We had a kind of motto—we had to ride it all out and then fade away…. From a very young age, we were all told we would die. So you take a teenager, you stick him in an institution with no parents; you tell him he’s only got a few years to live. And we just went crazy. What did we have to lose?

The experiences and circumstances of the DMD boys, while unique in some ways, also significantly overlapped with the remaining six participants as we discuss in detail below.

Positionings

Drawing from our Bourdieusian conceptualization of identities, below we explore both how participants were categorized and labelled in the social world and how their practices functioned to reproduce or resist these categorizations according to the habitus of each. Specifically, we interpret the men’s positionings in relation to dominant discourses of technologies, masculinities and disabilities.

Positionings and technologies

For men with DMD life is lived through bodies that are configured with medical technologies in particular ways that have implications for how their bodies are socially identified and personally experienced. We use the term “medical technology” to refer to a tool or thing designed for a given purpose but that may be used in multiple ways and exerts multiple effects in relation to other tools, practices, persons and places. Drawing from Timmermans and Berg’s (2003) “technology in practice” this definition occupies a middle ground between “technological determinism” and “social essentialism” by neither isolating technologies as “super-actors” with little accounting of how humans take up and ascribe meanings to technologies nor viewing them as tabulae rasa to be rendered meaningful by culture.

Although our focus here is primarily on complex medical machines, the definition includes the range of simple or sophisticated medical tools from drugs to patient records to catheters.

In the videos and interviews, technologies were represented or discussed as embodied extensions of the self and largely taken for granted until something occurred to bring them into consciousness, as is demonstrated in Harry’s comments:

Harry: It feels like I’ve had it (the ventilator) forever. It’s just like a part of my, it’s a part of me. It’s like an assistive device basically, not life support. I don’t think of it in that way.
BG: Do you think of your chair that way?
Harry: My chair more so. Because, since I'm nine
I've had, been in a chair, so it's basically my legs.

Harry suggests that he perceives his technologies as
continuous with his sense of body and self. Alan,
Brian, Nick and Alex made similar comments,
particularly in relation to their wheelchairs but also
when discussing accommodating to and “no longer
noticing” their tracheotomies and ventilators.

The con-corporation of flesh and machine means
that the “techno-body” is the lived body, both
inculcating social structures and expressing bodily
styles and practices. Acknowledging that bodies can
include inorganic matter strengthens Edwards and
Imrie’s (2003) enunciation of the particularity of
bodies in constructing the habitus. Body technologies
and enhancements can mediate identity as
profoundly as the biological body precisely because
the distinction between the two is fluid and
contingent. While all contemporary life is character-
ized by this connectedness of humans and
technology, there are profound differences between
for example, using a cell phone and using a
ventilator. As van der Ploeg (2004, p. 154)
comments, not all hybrid bodies are equivalent
and “one cyborg may be hurting more than
another”. Technologies are a source of enablement,
ence a form of capital, for people with disabilities
allowing them access to certain fields of leisure,
work or school but at the same time technologies
structure human interactions and contribute to
marking persons as “other” (Lupton & Seymour,
2000; Pape, Kim, & Weiner, 2002). The socio-
political context determines the meanings of tech-
nology and limits the extent to which individuals
can transform these meanings. Technologies are
thus implicated in the modes of daily existence
through which identity is continually negotiated.

The interconnectedness of bodies and visible
medical technologies had implications for how
participants were socially identified and categorized.
The men related numerous examples where the
strangers’ stares foregrounded their techno-bodies
and served as reminders of the pervasive negative
coding of their physical differences. For example,
Brian spoke about reactions to his ventilator
equipment:

Brian: People like on the street, they kind of
freak out when they see the hose.

BG: How do you feel about that?
Brian: It does affect me sometimes. I try not to let
it. But sometimes it does.

These kinds of encounters were relatively frequent
in the lives of the men who regularly ventured into
public spaces. However the same technologies could
also be sources of positive capital within certain
fields, particularly amongst other disabled persons.
For example, wheelchair speed, power and man-
oeuverability were markers of status and masculine
power within wheelchair sports. Five men spoke
with pride about the speed of their wheelchairs and
three displayed their driving prowess in their
videotapes. Alex’s entire 45-min video account was
of his weekly wheelchair hockey league game
videotaped by a friend, and George included an 8-
min scene depicting high-speed turns on a basket-
ball court.

In the institutional setting where the four “DMD
boys” had spent their youth, physical fearlessness
and aggression were valorized and demonstrated
through using wheelchairs to engage in violence. In
this field, such acts helped to establish and maintain
position in the institutional “pecking order” be-
tween groups of disabled residents that the men
likened to a “prison” culture:

Mike: (It) was more like a prison. There’s a lot
of fighting that you have...like gangs almost. I
was used to asserting myself more so I kind of
became one of the top guys.

Position within the hierarchy of the institutional
field was achieved and sustained through intimida-
tion of younger, emotionally or cognitively weaker
(but physically stronger) boys through physical
violence or verbal aggression. The appearance of
fearlessness coupled with technical prowess in
manipulating one’s wheelchair was a key source of
capital that helped sustain a dominant position
amongst the residents.

Positionings and masculinities
Masculinities, like identities in general, are
accomplished through everyday practices and stra-
tegies that change with time and place and emerge
from the interplay between habitus and field.
Bourdieu discusses gender as another arbitrary
principle of distinction, embodied in the disposi-
tions of social agents, that erroneously attributes the
division of sexual labour as flowing naturally from
the biological differences of male and female bodies

\footnote{BG is the primary author who conducted all interviews.}
The social world, he argues, constructs bodies as repositories of sexually defining principles of division such that the biological differences between male and female bodies appear as natural justification for the socially constructed hierarchical differences between the genders. Gender then, as an embodied principle of categorization, is one way in which social practices are ordered. Persons define themselves through practices that establish themselves in opposition to what they are not. For men this may be in relation to women but also to other groups of “feminized” men. Different masculinities emerge in relation to time and place, and the interacting structures, fields and positions of individuals or groups. Gender both structures and is structured by the practices of men and women and institutionalized discourses, beliefs and norms (Kimmel, 2000, p. 90).

The valorization and reproduction of stereotypical masculine traits described in the paediatric institution also arose in some of the men’s self-assessments of their worth as potential intimate sexual partners. In the following passage, Mike, who had been involved in sexual relationships in his past, discusses why the progression of his weakness has led him to stop dating:

Mike: It was just too frustrating. Because you have to be physical for a relationship to move forward, you know what I mean? I mean like, holding hands, it’s not the same thing. It’s still good. It’s just not the big picture.

Conversely, Harry who is 10 years younger than Mike discusses his relative lack of dating experience:

Harry: …I wanna play the male role, like take them places, pay for dinner, all that romantic stuff you see on TV and in the movies.

BG: Can you say more?

Harry: Gee, I don’t know, being a guy, a strapping male.

BG: So, strong? Do you mean that?

Harry: Not necessarily strong. I just mean like being a man, like sweep her off her feet kinda thing. Like there’s a male guy and a girl, and guys do certain things and girls do certain things.

The nine participants who discussed sexuality expressed taken-for-granted notions of what constitutes “normal” heterosexual relationships. Prominent in Harry’s quotation is a rather stereotypical view of masculinity and male roles. While these characterizations present a problem for him—he cannot achieve the “male role” he outlines—he does not question their legitimacy. Mike’s account suggests a perceptual schema whereby an intimate relationship is distinguished from a friendship by acts of romantic ritual and physical/sexual contact. Because he felt he could not functionally participate in these acts he rejected the possibility of a relationship and considered the entire dating field as unavailable.

It was relatively common for participants to reject fields such as dating, work or school where they understood (consciously or not) that they would be unlikely to have success given the tacit rules, stakes and capital they had internalized over time. It is interesting that Mike did not adopt a strategy to challenge and resist the dominant ideas of romantic love and penetrative sex that is commonly seen in research with differently politicized disabled persons (see for example, Gerschick & Miller, 1995; Shakespeare, 1999; Shuttleworth, 2000). Mike’s response, however, is consistent with his unique habitus formed from exposure to a given set of values, discourses and experiences.

Similarly Zack, in discussing what he said was the impossibility of ever “having a girlfriend” reproduces a particular understanding of positive masculine attributes:

Well, we don’t have anything to offer. No professional career. No real income. Even sexually in bed we can’t offer a lot.

Here Zack accommodates and reproduces dominant Western discourses of masculinity that suggest that in order to be regarded as “fully male”, men should have successful, lucrative careers and be able to sexually satisfy a woman in narrowly defined ways (Connell, 1995, pp. 77–78; Shakespeare, 1999). He measures himself against these norms and finds himself wanting without questioning the validity of these standards or their arbitrary nature. These notions have been incorporated into his habitus as a more or less natural and fixed set of norms and expectations.

Other forms of masculinities, however, emerged in the accounts through practices that adapted stereotypical markers of masculinity such as strength, intelligence, leadership, and autonomy and expressed them in non-traditional ways. For example, masculinities were established through practices where the men provided emotional, physical or financial support for others, including friends, family and, for five participants, pets.
Displaying emotional resilience also helped establish masculinities of independence. Brian described why he made the decision to commence ventilation without his mother’s input:

My mother was so uncomfortable. Her eyes started tearing up right away. It made me feel bad... She thought it was making me upset. And that wasn’t really true ‘cause I had dealt with it already. I had to or I wouldn’t be where I am now.

Brian conveyed how he supported his mother by taking the burden of decision-making away from her and only discussing ventilation after the decision had already been made. In this regard, he had learned that in order to survive (literally) he had to be mentally and emotionally tough.

These examples suggest that the men both reproduced taken-for-granted notions of what constitutes masculine capital and also engaged in practices that contributed to transforming these meanings. Yet the participants rarely openly questioned dominant masculinities or consciously attempted to create spaces for alternate masculine repertoires. Crossley (2001a) asserts that although practices may alter existing structures through the “dual processes of reproduction and innovative usage”, they nevertheless always arise in relation to existing understandings. Altering dominant discourses thus usually occurs slowly through incremental changes and exposure to alternate cultural forms. Transformative strategies, however, if enduring and taken up by significant numbers, will contribute to a process of social change and help to redefine masculinities. As Bourdieu said, “The partial indeterminacy of certain objects authorizes antagonistic interpretations offering the dominated a possibility of resistance to the effect of symbolic imposition” (Bourdieu, 2001, pp. 13–14). The men’s gender identity strategies are constructed in relation to dominant masculinities but they are not determined by them.

Positionings and disabilities

“Disability” is a social categorization imposed on men with DMD, formally and informally, in myriad encounters across social fields. From childhood, persons with DMD are labelled as disabled by official entities such as the medical and school systems. This categorization entitles them to certain benefits and access to programs but it also identifies them as belonging to a class of persons who are frequently marginalized across social fields. Multiple informal social encounters also reproduce and reinforce what eventually becomes a tacit understanding of social difference, a positioning outside of an accepted norm. Some participants recalled experiencing this difference quite vividly when they had been teased while attending “regular” public school, and even more so when they were in environments with other disabled children. For example, Alex discussed how he felt out of place starting at a school for disabled children:

Alex: It was weird for me. All these disabled people hanging around, I’m like, it bothers me, I’m like, I’m not used to this. But you kind of learn.

BG: Did you feel like you weren’t one of them, or why did it bother you?

Alex: Yeah, I didn’t feel it at the time, I’m like, I can do too much myself. I’m not really disabled, I thought.

BG: Did that change?

Alex: It changed, you kind of get used to it... I didn’t really like it too much, but you know you get used to it, sort of.

Alex’s statement, “You get used to it” alludes to the notion that one begins to know oneself as part of the group even if not by choice. This imposed identity that is multiply repeated through day-to-day existence gradually becomes internalized, even as it is being resisted. The resistance signals that there is something to be resisted, a new source of external positioning imposed first through official naming and then through social recognition as “disabled”. Notions of non-normative bodies as potential sources of negative capital are inculcated over time and participants work to resist, minimize or reformulate negatively coded disability identities.

Strategies for minimizing disability identities emerged in both the interview and the video accounts. George’s video provides a glimpse of how he was disposed to minimize his disability status in day-to-day interactions. In the excerpt below, a non-disabled friend had just asked George why he was wearing a camera and he is explaining the study:

George: Some physiotherapist. She wants to do a PhD.

Friend: On what?

George: People like me.

Friend: Who?
George: (loudly) LIKE ME.
Friend: Oh.

It is difficult to reproduce in text the subtleties of this exchange and how the two friends tacitly work to avoid any direct reference to disability. Both speakers through tone and body language, as well as their speech content, deflect and minimize George’s physical differences. The phrase “like me” is understood without elaboration and serves to avoid negatively coded terminologies such as “disabled”. After this brief exchange the topic of conversation was changed.

Participants varied in their usage of disability-related terminologies. For example, two of the DMD boys who were similar in age, background and living circumstances used the term “independent living” very differently. This is a commonly used and sometimes politically charged term in disability discourses that relates to disabled people having the resources available to live outside of institutions. Brian embraced this term and used it frequently in commenting on whether or not health and social services were facilitating his ability to live alone while Mike had a very negative reaction to the term:

Mike: I actually hate phrases like “independent living”. I hate that. Because you live like everybody else does. Why do you have to label what we do? I can’t see why we gotta to have a name for it, you know? Why does it have to be different? It’s the same thing everybody does.

Both participants lived in the community and directed their own care, but had different approaches to the term depending on whether or not its adoption, according to each one’s habitus, was understood as a positive source of capital. Brian had been exposed to disability rights activism through participation in a joint legal action he was involved with to improve living conditions in a supportive housing unit. He freely used the term, reflecting a set of values associated with a particular group within the disability community. Mike, on the other hand, actively rejected membership in this group and saw it a source of negative perceptions of disabled people. This is not to say he rejected a disability identity, but rather one of a certain type. So while Brian embraced a particular, somewhat “politicized” disability identity, Mike distanced himself from this group and worked to identify himself as similar to anyone who lives alone, disabled or not.

Accommodations to exclusionary socio-material environments

Although the participants experienced multiple challenges and barriers in their day-to-day lives, when directly asked what they would like to see changed, they had few complaints or suggestions for improvements, as is exemplified in the following passages:

BG: Is there anywhere you think you’d like to go that it’s difficult to go to, or you can’t go to?
Robert: Well, no. Most places are pretty good.
BG: So it sounds like you have kind of just built your life around the neighbourhood, and you’re not too concerned about getting outside of it?
Robert: No, I do occasionally go out of it. But I worry 'cause I can’t always go by myself in case I need suctioning.

This notion of “most places being pretty good” was repeated across the interviews with frequent references to how impairments are the primary cause of limited access:

BG: Any place that you’d really like to go that has accessibility issues?
Donald: Well not really. Any place is difficult to go to with the ventilator.
BG: And do you think that could be improved?
Donald: No not really.

BG: Would you like to be able to get out more in the community?
Donald: Ya I think so. But when you don’t go out much you get kind of used to it I think.

Here Donald suggests that accessibility problems can by-and-large be attributed to his ventilator. Both he and Robert appeared to have accepted that their impairments and particularly the need for suctioning are responsible for creating access problems. They more or less accepted that the obstacles in the world are fixed and could not be substantially altered. Although many participants faced risks going out on their own, none suggested that attendants should be funded to accompany them on excursions unrelated to health care or activities of daily living. Donald’s final comment above, that “you get kind of used to it” offers a glimpse into why these men—who are significantly isolated in comparison to almost any other social group—do not necessarily characterize their circumstances as such and/or feel there is nothing to be done. Donald’s case is particularly noteworthy.
because he rarely left his home where he lived with his parents. However this had become his usual way of being in the world that he is now “used to”. This state of being, of limited contact beyond his family and attendants, seemed to have its own logic that had sedimented over time and was now largely taken for granted as “the way things are”.

Even though the men had few complaints, it would be an error to suggest that changes are not needed to improve their circumstances. The men have learned to “get by” given what the world presents them with, and have found creative and innovative ways to achieve their identities and find meaning in existence. Strategies and practices were successful insofar as they facilitated day-to-day life and created spaces for personal meaning, but this is not to say that their situations could not be substantially improved in myriad ways that they would welcome. Funded attendant care for excursions into the community, reliable and accessible public transit, publicly supported recreation programs and available supportive housing are just a few of the changes that could substantially improve the lives of these men.

**Discussion: embodied marginalization**

The dominant theme that emerged from the study is what we have termed *embodied marginalization*. The accounts revealed that men with DMD are materially, socially and symbolically marginalized through the inaccessibility of the built environment, through social arrangements that limit their abilities to engage in community life, and through the myriad ways that their visible differences are negatively marked across social space. But perhaps most significantly, their marginalization was *embodied*. Through the processes of socialization, the dominant social order—the arrangement of material, social and symbolic exclusion—was internalized in the form of the perceptual schemas, dispositions and self-understandings that constituted their habitus. Embodied marginalization was expressed as a deep sense of resignation and low expectations manifest in the participants’ accounts and the conveyance of how they experienced marginalization as both “normal” and troubling.

We have drawn on key elements of Bourdieu’s work to discuss positionings in terms of identity practices, suggesting that how the men were externally categorized by acts of judging, naming and identifying affected how they positioned them-
incorporated into the habitus of all persons in the form of enduring dispositions and perceptual schemas. These schemas are used to assess, understand and know about the world, what Bourdieu calls “knowing without knowing”—who, for example, has power, is attractive, masculine, has something to offer, is successful, good, hardworking, etc. These schemas are deeply embodied such that persons come to know themselves and their “place” through them. The embodiment of marginality is a result of symbolic violence and is amongst the most powerful, damaging and enduring effects of the dominant social order on men with DMD. Symbolic violence is Bourdieu’s term for the often-imperceptible forms of domination exerted through internalized recognition and communication of the symbolic order amongst the members of a social space (Bourdieu, 2001, pp. 1–2). Members of a society come to know and accept the dominant social order as given even when that order harms some members, thereby reproducing a kind of ongoing violence that may not be recognized. So when Zack says men with DMD “have nothing to offer” he reproduces the dominant social hierarchies of abilities, accomplishments and potentials and, without the intention to do so, affirms his marginal position within social space. He does not wish to be marginalized, and he resists it by claiming power in other ways but he does not question the legitimacy of what counts as having “something to offer”.

We are not suggesting that the processes of embodiment of the social order are unique to Zack or other participants as men with DMD, but rather that these men are particularly disadvantaged by these processes that they share with others. For Zack and the other participants, the deep embodied understanding of the world durably deposited in the habitus was expressed in resignation and withdrawal. They had “got used to it”, as was seen to apply to so many of the aspects of their lives from rarely leaving their homes, to being stared at, to being limited in where they could go. So while the men claimed power in some fields and thrived with varying degrees of success within the context of their lives and prevailing conditions, within the larger social space, and across most fields, they were profoundly marginalized, isolated and excluded.

Implications

If one accepts Bourdieu’s thesis that symbolic violence is perpetrated through the dispositions of the habitus developed through repeated exposure within multiple social fields, the men’s paucity of complaints about lack of services and the preponderance of socio-material barriers can be seen as in keeping with an internalized logic of a prevailing social order. We believe this research has helped to make this logic more visible, not in order to point out to those exercising it the “error of their ways”. Indeed they are not in error—their behaviours, practices and orientations are revealed to be entirely reasonable given the conditions and circumstances of their existence—but this research aims to make visible the extent to which policies, services, the built environment and the symbolic realm of representation produce devastating effects that not only limit the social participation of men with DMD, but structure their identities. These embodied effects perpetuate the material, social and psychic isolation of men with DMD who work to carve out identities within a bounded corner of the social space and a limited number of fields. Getting out of the house, participating in sports, violence, maintaining friendships, having sexual intercourse—these are amongst the practices that the men use to distinguish themselves as masculine, as independent, as legitimate, as present. These practices are challenging, and sometimes risky, and attest to the tenacity of the men, but they are limited by current social and material arrangements and the hierarchies imposed by the dominant social order.

Challenging the dominant social order requires reckoning with the tenacity of enduring dispositions inscribed onto the bodies of its members. Dispositions impose limitations on innovation, imagination and action and can only be countered by making them explicit and public. Bourdieu (1997, p. 234) refers to this as the “margin of freedom” the site of struggle over the meaning, orientation and sense of the world where the major stakes in symbolic struggles are contested. Men with DMD may not always have a fully conscious awareness of the mechanism by which symbolic violence contributes to their marginalization, but they nevertheless respond to it with some unique and creative practices. So while the men might not be able to escape the dominant order, they also never wholly succumb to its impositions. As de Certeau (1984, p. xiii) suggests, one can escape the dominant social order without leaving it and thus deflect its power.

The belief that a better life with DMD is possible could be a rallying post for a change in thinking and policy. Given their current body-machine
configurations and impairments, men with DMD will likely always experience some degree of social and material limitation—if only because their physical impairments lead to fatigue, increased body work and further respiratory, musculoskeletal and gastro-intestinal challenges (for a related discussion of “impairment effects” see Thomas, 1999). But much could immediately be done to improve their situations, to create and expand spaces in their social worlds, to facilitate engagement and interaction when it is desired, and to do what can be done to facilitate contact with family and friends so that precious relationships can be maintained. The current policy disjuncture between “saving” persons’ lives using sophisticated technologies and establishing the means for them to participate in their communities must be acknowledged and addressed on multiple fronts.

Conclusion

In the paper we have extended a small but emerging strand in social health research that uses Bourdieu’s concepts to frame and investigate disablement. We have employed a particular reading of his work to explore the identities of technology-dependent men with DMD in terms of social positionings. To date very little research has been published about the experience of living with DMD and even less is known regarding survival into adulthood. The vast majority of DMD research and funding is focused on cure and prevention at the biological/genetic level. Any interest in understanding and improving the health and well-being of surviving adults is conspicuously absent. There has yet to be a sustained acknowledgement that adults with DMD and other technologically dependent disabled persons are legitimate members of the community and a population that will continue to grow into the future. Rigorous research is needed to understand their experiences and needs in order to develop appropriate care and programs, help them plan for adult futures and facilitate opportunities to live lives they value. This requires more than identifying and removing material access barriers but a trans-disciplinary engagement with the relationship between the macro-level social, political and cultural environment and the micro-level perceptions, understandings and activities of individuals. In studying identity in terms of social positionings, we hope to contribute to addressing this gap. Identity is produced and reproduced at the nexus of culture, politics, place, time and body. How persons are identified as members of social groups and positioned within group hierarchies manifests in their embodied understandings of themselves and has implications for their life chances and opportunities to pursue a personally meaningful existence. While men with DMD were the explicit focus of inquiry, the study has theoretical and practical implications for broader populations of persons with physical differences and/or chronic conditions, and for disability theory and research.

While the marginalization and exclusion of disabled people has been well documented, relatively little attention has been paid to the effects of symbolic violence and the mechanisms through which persons embody marginal identities. We suggest that a Bourdieusian line of inquiry represents a fruitful approach to understanding the experiences and practices of all persons, but particularly to address the marginalization of disabled persons who rely on multiple medical technologies.

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