Disability, Technology, and Place: Social and Ethical Implications of Long-Term Dependency on Medical Devices

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ABSTRACT Medical technologies and assistive devices such as ventilators and power wheelchairs are designed to sustain life and/or improve functionality but they can also contribute to stigmatization and social exclusion. In this paper, drawing from a study of ten men with Duchenne muscular dystrophy, we explore the complex social processes that mediate the lives of persons who are dependent on multiple medical and assistive technologies. In doing so we consider the embodied and emplaced nature of disability and how life is lived through bodies coupled with technologies and experienced as 'techno-body-subjects in situ'. Normative implications for theory and research, including bioethics research, are discussed.

Introduction

There are increasing numbers of persons with complex chronic conditions who are dependent on multiple medical technologies and live in community-based settings (Make et al., 1998; Jardine et al., 1999; Jeppesen et al., 2003). Beyond ‘quality of life’ debates regarding whether or not to offer complex life support technologies to these individuals, there has been little acknowledgement that technologically dependent disabled persons are members of the human community. Similarly little is known about how prevailing social, cultural, and material arrangements promote or hinder the pursuit of a meaningful existence for these persons. Medical technologies and assistive devices have paradoxical effects because, although designed to sustain life and/or improve human function, they can also contribute to stigmatization and socio-material marginalization (Lupton & Seymour, 2000; Pape et al., 2002).

To explore the complex social processes that mediate the lives of persons who are profoundly dependent on medical and assistive technologies, we conducted ten detailed case studies of men with Duchenne muscular dystrophy (DMD) who rely on long-term mechanical ventilation. Elsewhere we have drawn from the work of Pierre Bourdieu to discuss how these men’s identities were constructed in relation to
dominant discourses of disability, masculinity, and technology (Gibson et al., under review). In this paper, we focus on exploring the embodied and emplaced nature of disability and how the body-in-situ is experienced as a ‘techno-body’. In so doing we consider the intersectionality of bodies, technologies, and places, and the implications for theory, research, and policy.

The Study

The study involved qualitative interviews and independently created ‘video diaries’ of ten men with DMD living in a Canadian city. DMD is a progressive genetic condition affecting males that is usually diagnosed in the pre-school years and involves progressive weakening of skeletal muscle as the child ages. Weakness leads to a loss of physical functional abilities including the eventual inability to breathe independently. Prior to the 1990s, boys with DMD could expect to live only into late adolescence, but with ventilation, they can now survive well into their thirties and potentially longer (Yasuma, 1996).

The men in the study ranged in age from twenty-two to thirty-six years old. To be included, participants had to be reliant on long-term mechanical ventilation for all or part of the day. Each participant was interviewed twice and provided with a hands-free video camera system over the course of a week to allow him to create an independent video of ‘who he was’ and ‘what life was like’. Ethics approval was obtained from the local university research ethics board. Five of the participants lived in residential homes with their parents, three in supportive housing apartments with on-site attendant care services, and two in a long-term care facility. Consistent with the progression of DMD, all of the men used wheelchairs for mobility and had minimal functional movements of their upper extremities. They relied on hand or mouth sticks, adapted remote switches (i.e. environmental control units), or personal assistance for tasks that required holding or manipulating objects. Nine of the men had permanent tracheotomies while one was ventilated via a facemask at night only. All participants required manual assistance with eating and five had permanent gastrostomy tubes (a stomach tube that is accessed external to the abdomen) to supplement their diets. All could speak without aids. None of the men reported impaired sense of touch, sexual or cognitive functions, and these functions are not normally affected by DMD.

In what follows we sketch out a conceptualization of the complex relationship between ‘extraordinary bodies’, technologies, and places by drawing on the men’s interviews and video accounts. ‘Extraordinary bodies’ is a term coined by Rosemary Garland Thomson to refer to physically different bodies that are culturally and/or officially marked as ‘disabled’ or different (Garland Thomson, 1997). There is a paucity of literature that examines the experience of living with a technologically enhanced extraordinary body and even less that theorizes the relationship between individuals and the socio-material places in which they are immersed. In addition, although much has been written about the interface between the body and technology, there is little research that has focused on disabled bodies and disability technologies. Before discussing these themes further, however, we first position our
work in relation to current writings in disability theory that explore how disabilities are both embodied and emplaced.

**Conceptualizing Disability**

In the last three decades, scholars in the emerging field of disability studies have developed the ‘social model’ of disability to challenge biomedicine’s conceptualization of disability as an individual problem resulting from a biological impairment. The social model rejects approaches that focus on individual adaptation or coping and instead draws attention to the dominant ideologies imbedded in ‘ableist’ norms and practices that exclude disabled people from society and relegate them to ‘special’ areas (Hahn, 1988; Barnes, 1996; Oliver, 1996). The crux of the social model is the distinction made between impairment and disability. ‘Impairment’ is defined as ‘lacking part or all of a limb, or having a defective limb, organ or mechanism of the body’ and ‘disability’ as ‘disadvantage or restriction of activity caused by contemporary social organization’ (UPIAS, 1976). Within the model, it is the disabling environment that excludes people from full participation in society, rather than their biological impairments.

In focusing on the social production of disability, proponents of the social model have been successful in raising awareness regarding the oppression of disabled people, and in shifting policy debates from medical to political spheres (Hughes & Paterson, 1997; Silvers et al., 1998, pp. 74–76). The model, however, has been criticized for inadequately representing the lives and experiences of disabled people and the multi-dimensional nature of social marginalization and exclusion (Kitchin, 1998; Silvers et al., 1998; Gleeson, 1999; Thomas, 1999; Imrie, 2000; Freund, 2001). Tensions arise between the focus on individual persons and experiences versus an emphasis on the disabling social world. Several theorists drawing from post-conventional and critical frameworks have begun to sketch out models of disability that integrate the social with the personal by focusing on how disability is both embodied (Hughes & Paterson, 1997; Williams, 1999; Turner, 2001) and emplaced (Kitchin, 1998; Gleeson, 1999; Freund, 2001). The former refers to the social model’s focus on the binary division of impairment and disability with little consideration of the lived body, and the latter refers to its inadequate consideration of the role of space and place in constituting disability.

**Bringing in the Body**

Building on the work of Merleau-Ponty, scholars such as Turner (1984, 1992, 2001), Crossley (1995), and Shilling (1993) have argued for a conception of the lived body that transcends Cartesian mind/body dualism. They posit that human beings should be viewed as both having bodies and being bodies. Subjects perceive the world and the self through an integrated, lived body with no distinction between the psyche (mind) and the corporeal body. This integrated body is both sentient and sensual and thus perceives and engages in the world as a body-subject (Crossley, 1995). Body-subjects both experience and create the social world.
Within the social model of disability, the body is largely silent, lacking a history and devoid of its materiality. The absence of the body in the social model was originally intended to discount prevailing explanatory medical models that focused on disability as being constituted by biology. As Shakespeare states:

The achievement of the disability movement has been to break the link between our bodies and our social situation, and to focus on the real cause of disability, i.e. discrimination and prejudice. To mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing on evidence that disability is ‘really’ about physical limitation after all. (Shakespeare, quoted in Oliver, 1996, p. 39)

Critics argue, however, that while disability is never exclusively physical, there is nevertheless a somatic component to disability that cannot be dismissed (Bendelow & Williams, 1995; Hall, 2000). Pain, nausea, and weakness exert effects that cannot be fully addressed by changes to the socio-material environment. The social model discounts these bodily realities as mostly unimportant or non-contributory to the disablement process. Yet as many have suggested, any impairment that is life threatening or causes persistent somatic discomfort needs to be acknowledged as part of disability. As Liz Crow writes:

The silence prevents us from dealing effectively with the difficult aspects of impairment. Many of us remain frustrated and disheartened by pain, fatigue, depression and chronic illness, including the way they prevent us from realizing our potential...yet our silence has made many of these things taboo and created a whole new series of constraints on our self-expression. (Hall, 2000, p. 25)

Williams (1999) argues that impairments such as pain, fatigue, and the inability to breathe can be adequately addressed and understood only by a consideration of the physical body. Over-socializing the body leaves no theoretical room for how individuals experience their own materiality and how it is signified. A richer explanatory model of disability, he suggests, includes considerations of the material body and how it structures interactions and experience. Hughes and Paterson (1997) do this through a reinterpretation of impairment and disability that collapses the corporeal, the personal, and the social into a unified embodied experience that admits the reversibility of disability and impairment such that disability is embodied and impairment is socio-political. They outline how the integrated body-subject is the basis of experience such that ‘disability is...experienced from the perspective of impairment’ (Hughes & Paterson, 1997, p. 335). Oppression, instead of existing only ‘out there’, is also an embodied experience. ‘Suffering’ is reconfigured as the mutual engagement of social limitations and impairment, which together produce physical and existential distress. Such a view of suffering does not reduce it to biological dysfunction; on the contrary, it is rooted in the social and material environment and how a person experiences impairments in a given place and time. This integrated notion of the
body provides a means of investigating individual experience at the nexus of the corporeal and the social.

**Bringing in Place**

Both the social model and more recent contributions from the sociology of the body have been criticized for neglecting to consider the social organization of space and the role of place as contributing to the production of disability (Freund, 2001). Despite the social model’s implicit focus on space, some suggest it has largely failed to represent the intricacies of how spatial organization both ‘constructs bodies and offers bodily possibilities and constraints’ (Freund, 2001, p. 694). As a corrective, geographers and other scholars have proposed the ‘body-in-situ’ or a ‘spatialized body’ as a point of departure for considering disability (Kitchin, 1998; Gleeson, 1999; Imrie, 2000; Freund, 2001).

Gleeson (1999) discusses how disability is manifested and reproduced in two overlapping realms of social relations: first, through prevailing socio-political power relations, and second, through everyday experiences of physical and cultural exclusion. The impaired body is conceived of as located in particular social and material spaces, the elements of which interact to produce disability. How disability is perceived or experienced will vary according to these interacting factors. Settings are thus reconceived as not merely locales where interactions occur but as places imbued with meanings and taken for granted rules that mediate interactions and the social positionings of persons. A rehabilitation centre, a classroom, a shopping mall all suggest a certain way of interacting and behaving through the structure of the building, the arrangement of furniture, the cues of who occupies which spaces and which spaces are off limits to certain people and accessible to others (Freund, 2001). The social and the spatial are mutually entwined and constitutive insofar as social relations and processes cannot exist outside of space, but are constituted in and through particular social structures or ‘spatialities’ (Imrie, 2000). Gleeson is careful to point out that these ‘geographies of disability’ are specific to a given place and time. In addition, the focus on the marginalization of disabled people does not imply that they exist completely outside of mainstream social life. Inclusion and exclusion exist in a dialectical relationship with disability emerging from participation in core social relations. The geographies of disability thus must be ‘mapped from the co-ordinates provided by the cultural, political-economic and spatial organization of society’ (Gleeson, 1999, p. 54).

Empirical studies have applied these ideas in investigating the socio-spatial dimensions of disability with specific populations, albeit in very different ways. In an early study, Rowles (1978) used qualitative case studies to demonstrate how older people with diminishing physical abilities made adjustments over time to maintain harmony between a sense of self and the manner in which each constructed and related to his or her ‘geographical lifespace’. From a positivist/behaviouralist perspective, Golledge has examined the practical problems of disabled people and particularly those with visual impairments in negotiating the built environment (Golledge, 1993; Golledge et al., 1996; Golledge & Stimson, 1997). More recent work has focused on the socio-spatial construction of the disabled body and the politics of exclusion. For example, Skelton and Valentine (2003a, b) explored
hearing-impaired youths’ experiences of exclusion and inclusion through processes of marginalization and resistance across a range of socio-spatial institutions. Their work focuses on how young persons negotiate their identities and social positions in relation to the Deaf community and Deaf culture. In research that focused on ‘the embodied human subject within the spaces of daily life’, Dyck (1995, p. 308) found that women with multiple sclerosis experienced progressively shrinking social and geographical worlds, which rendered their lives increasingly hidden from view. In a similar vein, Moss (1997) examined the geographies of older women diagnosed with rheumatoid arthritis using a conceptual lens that considered the ‘complex entwinement of space, body, health and illness through a radical body politics’ (p. 23). She showed how women’s negotiations of spaces through embodied social practices are intricately linked to their own conceptions of chronic illness and disability.

This emerging body of research demonstrates how conceptualizing disability as embodied and emplaced builds on the social model while addressing some of its silences. The impaired body is located in socio-material places and political/historical contexts that intimately intertwine in the production of disabilities, and more broadly of subjects and subjectivities. While these contributions are critical to understanding the complexities of disability and the experiences of disabled people, to date the role and place of medical technologies has not been addressed. Research has suggested that medical assistive technologies may both ameliorate and contribute to disablement (Locker & Kaufert, 1988; Pape et al., 2002; Sapey et al., 2004), but a richer appreciation of these processes is aided by working through a conceptualization of technologies in relation to embodied and emplaced disabled subjects.

### Bringing in Technologies

The term ‘technology’ has a range of definitions and conceptualizations across theoretical traditions. We have drawn from Timmermans and Berg’s (2003) articulation of ‘technology-in-practice’ as it applies to medical tools and practices. This approach understands a technology as 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. While our discussion is limited mainly to the sophisticated medical machines including wheelchairs and ventilators that were central to our study participants’ lives, our definition of medical technologies is broad and includes not only complex machines but the range of simple or sophisticated tools from drugs to patient records. Furthermore, we agree with Timmermans and Berg that ‘it is often difficult to single out one technology as an isolated device because technologies are embedded in relations of other tools, practices, groups, professionals, and patients’ (2003, p. 104). How technologies are used or understood may vary between these networks.

Timmermans and Berg draw from theoretical work in the field of science studies by Bruno Latour, Michel Callon, and John Law, among others, to address problems of ‘technological determinism’ and ‘social essentialism’ in the study of medical technologies. Technological determinism, they suggest, tends to demonize relatively new tools and associated practices as founts of social problems with little accounting of how humans take up and ascribe meanings to technologies. Social essentialism,
at the other extreme, views medical technologies as *tabulae rasa* to be rendered meaningful by culture. Technology-in-practice occupies a middle ground between these positions:

Unlike the view of technology in social essentialism, it is not a blank slate to be interpreted because technology itself co-ordinates clinical and organisational aspects of health care. Neither is technology a ‘super’ actor stifling all other interactions as presented in the strong form of technological determinism; its agency is constituted by others and in turn constitutes the actions of others. (Timmermans & Berg, 2003, p. 104)

A technology-in-practice approach allows for an examination of technologically augmented bodies in order to gauge what assistive, life saving, or alternative goals medical devices help accomplish or confound. Furthermore, in similar ways to our conceptualization of the body, it allows for a consideration of both the materiality and the cultural significance ascribed to technologies and the relationship between the two. Relevant effects—ethical, social, personal, or otherwise—that emerge through the usage of technologies will depend on how they are experienced and transformed within and across social spaces. Below we elaborate on these themes further through an examination of the study participants’ accounts.

**Techno-Body-Subjects in Situ: Participant Accounts**

*Connectivity of Flesh and Machine*

We begin by exploring the relationship between impaired bodies and medical technologies. The men’s interview and video accounts suggested continuities and breaks between bodies and machines that varied among participants and also within individuals’ experiences. The following excerpts from Harry and Nick’s interviews (all names are pseudonyms) provide examples:

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.

Nick: I’m used to being in a chair now. If I was able to walk, I’d rather be in the chair than walk.

BG: Tell me why.

Nick: I’m just used to it. Like if I had the opportunity, I’d rather have my arms than my legs.

BG: Okay. Cause you’re so used to getting around in your wheelchair?

Nick: Yeah, mostly. It’s so easy. I’m so used to being in a chair. It’s just the way I am.

Although they struggled with making themselves understood, Harry and Nick both suggest that their technologies have become incorporated into their self-understandings and largely taken for granted. Interestingly, Nick, when pressed, reflects that he would rather have (functional) arms than legs, powerfully expressing not
only an embodied relationship but also a qualitative assessment of its attributes (‘it’s so easy’). As a means of mobility, the wheelchair has some advantages over walking—speed and ease—and to that extent is not perceived as a disadvantage.

These kinds of statements call into question the boundedness of the body, where the body begins and ends, or how it should be defined. Haraway (1991) has described the fluid boundaries between all persons and technologies and argues that all contemporary persons are person/machine hybrids or cyborgs. She suggests that all contemporary activity is mediated by technology and the limits between where the person ends and the machine begins are becoming increasingly blurred. Smith (1999) suggests that one can only answer the question of where the body ends and the machine begins in highly localized contexts. Paraphrasing Felix Guatarri, he posits that ‘the technical object is nothing outside the technical ensemble to which it belongs ... it always contains humans inside it and before it and contains within it a non-human enunciation’ (para. 6). This echoes Bruno Latour’s notion of the quasi-object that is always also a quasi-subject, reiterating that the distinction between ‘objects’ and ‘subjects’ is not an ontological given (Latour, 1996, p. 213). Technologies are inscribed with meaning by humans, but they also exert effects. Instead of separating the body into biological and technological parts, the ‘techno-body’ can be considered a lived-through assemblage, a ‘concorporation’ of flesh and machine, whose configuration and meaning changes with time and place.

These relationships are, of course, not limited to persons labelled as disabled. Just as all persons instinctively perform tasks without reflecting on how to manipulate specific body parts, they also employ technologies as extensions of the self. Processes such as operating a computer or driving a car have been integrated into corporeal schemas whereby, without reflecting on the process, it can be carried out habitually. Crossley (2001) refers to this ability as ‘knowing without knowing’ and points out that it is not only one’s own body that one knows, but also the socio-material environment in relation to the body. Bodies have a pre-reflective sense of how to move about and function in familiar places.

The use of a wheelchair illustrates this point. In Harry’s video he narrates a (wheelchair) drive around his neighbourhood. He talks the viewer through his bodily manoeuvres as he negotiates bumps, potholes, and turns on the pavement and in so doing consciously reflects and remarks on those movements that he normally performs automatically as embodied practices. Even so, much of what he is doing is not commented upon but is performed through continuous subtle and automatic adjustments. As a viewer, all one can see is what is in front of Harry, and the bumps and jars he encounters as the image shakes and jiggles. He recreates the sense of negotiating the terrain, and how his biological body and wheelchair function as a seamless unit to achieve performance. He drives the wheelchair but in so doing is coupled with it, taking on its velocity and acting in accordance with its functionality. Like any accomplished vehicle operator, he does not think through the individual steps involved in manipulating his chair, nor does he consciously calculate speed in relation to the terrain or wheelchair dimensions, but rather the body habitually reacts to the situation.

Contemporary life is characterized by this connectedness of humans and technology; there are, however, profound differences between using a cell phone
and using a wheelchair or ventilator. Men with DMD live life through bodies that are
configured with assistive technologies in particular ways that have implications for
how their bodies are socially identified and personally experienced. Technologies are a
source of enablement for people with disabilities, but at the same time technologies
structure human interactions and contribute to marking disabled persons as ‘other’.
The social world shapes the meanings of technology and will thus limit the extent to
which persons can transform these meanings (Lupton & Seymour, 2000).

Disabled people have reported both positive and negative experiences
with technology depending on the context and the relative social acceptability of
various devices (Lupton & Seymour, 2000; Pape et al., 2002). Technology users are
not only limited by physical barriers in the community, but also may be stigmatized
because their technologies assign to them a social meaning. While technology may
(or may not) decrease physical sequestration, it does not necessarily address social
marginalization or ameliorate social suffering. Two participants, for example,
discussed how their physical differences were a source of social rejection. In the first
passage, Zack is discussing an encounter with an ‘escort’ he has hired over the
telephone:

Zack: The worst incident I ever had (was when) a lady walked in, took one look
at me in bed, started crying and ran out. That’s a little humiliating! I’ve had
others walk in, take one look and walk out.

In this next passage, George, with some prompting, discusses dating in relation to his
visible differences:

BG: Do you think it’s going to be difficult for you to meet someone?
George: I don’t know. It could be.
BG: Do you think it makes a difference that you have a disability?
George: I think, yeah, it does.
BG: In what way?
George: Cause they see the wheelchair first, before the person.

In addition to these kinds of comments, nearly all of the men spoke about being
’shy’ either currently or as children/adolescents. Discussions of shyness were often
related to risks involved in initiating new contacts with others, especially girls/women
(all participants self-identified as heterosexual). Some expressed worries, like George,
that potential partners ‘see the chair first’ or ‘only want to be friends’. Shyness was
tied to negative self-assessments and fear of rejection and, for many, was coupled
with a lack of experience and exposure to mixed gender social situations. The men
also spoke of negative experiences in their younger years such as teasing, staring, or
rebuffs, which would have contributed to shaping perceptions of new encounters.
How the men’s techno-bodies were socially identified mediated their perceptions of
self and social position. Through the internalization of social norms that exclude and
devalue extraordinary bodies, the men have learned to ‘know their place’ within the
social order. In other words, through immersion in environments where their techno-

bodies were stigmatized or rejected they had learned to conceive of their bodies as
inferior to their able-bodied peers. This was manifested in their reports of shyness and avoidance of certain social fields of interaction.

The men’s accounts further demonstrate how the techno-body mediates experience and self-identities. People may ‘see the chair first’ but they do not see the wheelchair in isolation from the body-subject. The techno-body-subject is perceived as a negatively coded whole and rejected because of the stigma attached to impaired bodies and assistive technologies. This social experience is quite different from an interface with pervasively valorized and masculinized technologies such as cars or computers (Connell, 1995, p. 148). A striking example of this is Zack’s discussion of how he would prefer to be/have a very different kind of techno-body. He recognized that his technologies were negatively coded and reproduced those understandings in his evaluations of himself. When pressed on the differences between his body and that of a science fiction character he admired, he had this to say:

BG: So when we talk about Luke (character from the film Star Wars) losing his hand and getting it replaced with the cybernetic one, how is it different, or is it different?
Zack: It’s (pause). It’s not as advanced.
BG: The technology you use?
Zack: What I would really like is to get rid of this body and be in a virtual reality or cybernated body.

Despite these kinds of reflections, the accounts suggested that the men’s medical devices were often taken for granted as embodied extensions of the self until something occurred to bring them into consciousness. Harry’s descriptions of his ventilator and his wheelchair as ‘parts’ of him and as assistive devices can be likened to how persons commonly describe biological body parts. Depending on context, one may refer to the body as object or subject, take body parts for granted as part of oneself or objectify and even symbolically separate/disassociate from them when they dysfunction. In addition, body parts are ‘owned’ elements of the self that can be violated if touched without permission. Harry commented that it bothered him if others would sit in his chair when he was not in it. Similarly, Zack, in discussing the unwritten rules of adolescent rivalries that were part of his life growing up in a paediatric institution, demonstrated this point in discussing an altercation with another resident:

Zack: He went out into the hall, drove around my chair and tried to break it.
And that was a no-no. If the guy’s not in the chair, you don’t fuck with the chair.

Participants thus seemed to experience their selves as dichotomies of minds and (techno-) bodies and as coherent techno-body-subjects. For both Harry and Zack, when their bodies were separated from their wheelchairs, there was a continuity of the self across biological and technological parts even though these parts were physically dispersed in space. This suggests that where the body begins and ends is
experienced in a fluid relationship, where selves leak in and out of bodies and machines regardless of where they are located in space (Gibson, 2006).

Positive characterizations of electric wheelchairs were much more common among the men than positive characterizations of ventilators:

BG: I’m interested in the fact that you’re always attached to your ventilator. Does it feel like it’s part of who you are or is it something that you ‘use’?
Mike: No it’s annoying.
BG: It’s annoying?
Mike: Pain in the butt ya. Cause now I’m tired more than I used to be. I have less hours to be in my chair to do what I want to do. I’ve got to waste time doing stuff with the ventilator when I could be going out.

Mike focuses here on the negative consequences of using a ventilator and conflates it with his breathing impairment—‘now I’m tired more’. In this respect, it is perhaps akin to an organ that is taken for granted until something goes wrong. The ventilator in this sense is also an extension of the body and self but is not imbued with the same high status as the wheelchair. Nick and Alex’s responses were somewhat more typical in conveying a sense of the embodiment of ventilation technologies. They discussed tracheostomy and ventilation as positive choices that they both wished they had initiated sooner:

Nick: I thought of it, but I was scared to do it. But when I got it, it changed. I opened my eyes. It was like—when I got it, afterwards it was nothing. Like, I should have done it a long time ago.
BG: Oh really. So what were you worried about before that?
Nick: I guess I was scared to get it, I don’t know.
BG: Were you worried about the way it would feel, or the way it would look?
Nick: Both.
BG: And what do you think now?
Nick: I don’t really notice it sometimes.

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Alex: I wasn’t used to my trach (tracheotomy) being moved around all the time, and touched, like that’s what annoyed me at first (when I started ventilation). But now I don’t even notice it’s there anymore. Same thing when I got the trach. I could feel it, but then after a while I don’t even notice.

Although these were typical stories there was a notable exception. Donald, who required the most frequent suctioning (an uncomfortable procedure to remove airway secretions) of the study participants (about ten times per day), had this to say:

BG: Can you tell me how you feel about the ventilator?
Donald: Well it’s good in that it lets me live longer and breathe better, but there’s a lot of difficulties associated with it. Just with the care and maintenance of the ventilator and the tracheostomy and suctioning.
Donald was among those who felt most isolated by his condition and most strongly expressed feelings of depression. He rarely left his home and never went out alone. Much of the activity of his household focused around his care needs. His video focused on providing advice to potential ventilator users about decision-making, the amount of work associated with ventilation in terms of suctioning, care of equipment, and the consequences such as difficulties with going out. Thus, although for most of the participants wheelchairs and ventilators were incorporated into their perceptions of body and self, this was not a universal experience. Donald did not appear to have ‘gotten used to it’ in the same way, seemingly because of the burdens he foregrounded in his discussions.

These examples demonstrate how bodies and technologies are intimately intertwined in the production of disabilities and social exclusion or inclusion. But we have only touched on how the organization of space is implicated in these relationships. Below we discuss some of the participants’ micro-geographies in order to further demonstrate this relationship with a more explicit focus on how disability is emplaced. Through this discussion we reveal how the participants were often marginalized and excluded from participating in their communities.

Participants’ Micro-Geographies

The study participants’ personal micro-geographies, that is, where, when, and how they acted and interacted in various social and material places, illuminate how place is integral to the production of disablement both through the prevailing socio-political power relations and through the mundane everyday experiences of physical and cultural inclusion or exclusion. How the men occupied and moved across space at the scale of their homes and neighbourhoods demonstrates the complex relations between extraordinary bodies, technologies, and places in producing disabilities.

The men’s day-to-day lives 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 excursions into the community. Although two of the men rarely left their homes except for medical appointments, the remainder generally went out between two and five times per week in fair weather. ‘Going out’ and ‘being part of the community’ was a central occupation of their day-to-day lives. Depending on the length of the excursion, going out could require considerable planning and effort, including coordinating excursions with meals and toileting needs, dressing for the weather, ensuring batteries are sufficiently charged, and packing suctioning equipment.

These excursions were important in two senses. First, just getting up and out was important and linked with a sense of being part of the life of the community regardless of whether or not one met up with anyone. Second, it was also important to facilitate interaction with friends and acquaintances. Participants planned some excursions either to meet up with friends or with the expectation that they would likely run into someone. For example, in George’s video there is a long scene where he looks out of his apartment window to see if any of his friends are outside and, having spotted someone, takes the viewer on an excursion into his neighbourhood to meet up with friends and acquaintances. Some of the people he meets he knows well,
others he only greets and moves on. What is notable is that this scene occupies about two-thirds of his seventy-minute video, the remainder of which was filmed in his room showing his computer-based hobbies including music, games, and movies. This example, along with numerous comments from George and other participants, emphasized the importance of social interaction for the men (none of whom were employed, attending school, or engaged in any other regular occupation). The only structured social engagement that five of the ten men participated in was weekly seasonal organized wheelchair hockey.

Mike’s comments provide a further example:

Mike: I don’t go out as much as I want to. Or when I go out, I have a great time, then I come back and I feel you know, blah, again. I come down. You know what I mean?
BG: Do you mean mood wise?
Mike: Ya, then the next day I want to go out again, but I can’t. There’s no one to go with me. . . . But in the summer I go out a lot more. . . . It’s just right now if I’m not going out it just gets more, like, [I ask myself] ‘Why am I going thru all this for nothing?’ I get up for a video game, go lay down . . . it’s very hollow. You know what I mean?

Mike’s statement regarding having ‘no one to go with (him)’ refers to the lack of funding for support workers to accompany ventilator-users on community excursions because the activities do not qualify as either medical necessities or basic ‘activities of daily living’ such as bathing or eating. If he went out on his own, Mike would risk ventilator disconnection or mucous plugging of his tracheotomy tube, either of which is potentially fatal.

The frequency of excursions dropped dramatically during the cold winter months. All of the men said they left their homes far less often in the winter, to the point that many remained inside for weeks or even months at a time. During these periods they would rarely see anyone except paid caregivers or family members. Cold weather, rather than snow, was cited as the primary barrier. The men complained of the lack of appropriate warm weather clothing available to them. Due to their limited mobility, putting a coat on and taking it off were highly effort intensive. Instead, they used blankets and sheepskins, which were largely inadequate at maintaining warmth. The men complained that they felt the cold intensely. This is likely related not only to inadequate clothing but also to the effects of decreased muscle mass and movement (at least six participants weighed less than 100 pounds). Further, most could not wear gloves or mittens because of the sensitivity needed to feel the lever or joystick that controlled their wheelchair functions through subtle movements of the fingers and wrist. In this Canadian context, the limitations of available cold weather technologies to address the men’s impairments meant that they spent most of the winter months sequestered in their homes despite an ongoing desire to be out in their communities.

Body, place, time, and technology thus intersected in the production of disabilities whereby technologies designed to address impairments contributed to others, and technologies like the wheelchair designed to address physical barriers could not be
mobilized in particular places and times because of other unanticipated problems. These physical limitations produced a social sequestration making it impossible for the men to participate in social and political life, limiting their citizenship, and rendering them invisible. Furthermore, as the men aged and their weakness progressed, they experienced an increasing shrinking of their worlds that paralleled their social trajectories. Ventilation was often commenced between the ages of seventeen and twenty, around the time when participants were completing or had just completed secondary school. For many, the combination of generally reduced physical access and loss of an important space for social interaction resulted in a significant restructuring of their socio-spatial lifeworlds with an increased focus on home and neighbourhood. The dynamic shifting of men’s physical abilities, usage of technologies, and changing social roles structured how they negotiated and redefined spaces over time.

The participants accepted varying degrees of risk associated with moving about in the community unaccompanied. The following stories from Harry and Alex reveal their individual approaches to risk, and some of the potentially fatal incidents they had experienced as a result.

BG: So what if you’re out for a walk in the neighbourhood and you need a suction, does that limit how far away you can go?
Harry: Yeah it does. Like on my own, I’m only away for fifteen minutes at a time, maybe twenty minutes at the most. And I tell whoever helps me get outside; I tell them the route I’m going to take so they can find me. And in case my vent (ventilator tubing) ever pops off I tie it on with a string so it can’t come off ’cause that would be another issue. Three years ago I just went around the block and it popped off. Thankfully, I just turned around and drove home.

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BG: Are you worried about safety at all?
Alex: I’m not going to let fear ruin me living my life. I do believe that when your time’s up, it’s up. No matter how safe you are, no matter what you’re doing, it’s just, that’s it, it’s over. So I’m like, I’m just going to go and live every day, that’s it.
BG: Do you bring suctioning equipment with you?
Alex: Yeah. I always bring everything with me.
BG: Have you ever had to use it?
Alex: I had a cab driver suction me once. I didn’t tell him what it was going to be, and that it was gross or that he could hurt me or anything.... Still, he suctioned me, suctioned it out. It grossed the hell out of him, but he cleared my airway.

These passages demonstrate the participants’ varying approaches to risk, which ran the gamut from never going out alone, to staying close to home when alone, to completely accepting the risks and travelling farther afield. All of the men who did venture out on their own discussed tradeoffs between being safe and being able to access the community independently. For those living in institutions or supportive housing, staff members were not paid to accompany them for ‘leisure’ purposes.
This meant the men had to make tradeoffs between serious risks of disconnection and, as Robert put it, 'living the little bit of life that you have'.

Although faced with similar kinds of material barriers, the participants’ responses varied depending on their life histories, priorities and dispositions towards personal risk. Spatial withdrawal was more acceptable to Robert as he restructured his priorities to focus on maintaining key familial relationships in the home, and with friends in the immediate neighbourhood. Although he had less contact with school friends and expressed some regret about this, he had more or less adjusted to his shrinking socio-spatial lifeworld. Alex, on the other hand, lived in a long-term care facility populated by mostly older residents where he had few opportunities for social interaction with peers and limited contact with family. Being out in the world was important to his sense of ‘being alive’ and his identity as a young man. He was less willing to give up his access to the community and as such incurred significant physical risks. In so doing he resisted marginalizing social and material forces that would relegate him to a sequestered institutional existence and expressed his presence in one of the few modes that was available to him. Even though Robert and Harry may appear resigned to the shrinking of their lifeworlds, by venturing out alone within their neighbourhoods they also actively negotiate the boundaries imposed by the incongruence between their techno-bodies and spatial environments, but do so with a different set of priorities.

For excursions outside of the immediate neighbourhood, transport could be a major issue. Participants travelled either by a publicly subsidized accessible bus service or with an adapted family-owned van. Using wheelchair transit required planning. Trips had to be booked at least one day beforehand. Bookings occurred within a thirty-minute window so there was often significant waiting time. Also, travelling between two municipalities in the same city required coordination of two different bus services which could cause considerable wait times and additional costs. The advantage of publicly funded wheelchair transit was its low cost—the same fare as for the rest of the municipal transit system—and it provided door-to-door service. Door-to-door service, however, also meant that participants often had to travel over considerably extended and time-consuming routes in order to pick up or drop off other passengers.

Finding appropriate housing was a pressing and ongoing issue for most of the participants, regardless of their current living situations, and was closely linked to their engagement in personal, social, and civic life. Issues that arose included the lack of available supportive housing units in the city and long waiting lists. This forced participants who wanted to live independently to accept whatever became available, often in areas that did not meet their needs or where they felt unsafe. For example, one person avoided a park across from his building because of the ‘drug dealers’ of whom he was wary. For others, their housing location limited the ability to visit friends or meet new people. One participant complained that he was very far away from most of his friends and extended family who lived in a suburb on the other side of the city.

In Canada and elsewhere in the developed world, housing for disabled people, although significantly improved over the last twenty years, remains unavailable or inadequate with ‘ghettoisation’ in urban ‘zones of dependence’, often in unsafe neighbourhoods (Dear & Wolch, 1987; Gleeson, 1999). The physical layout of
neighbourhoods and buildings limits access to the community and confines disabled people to particular zones of interaction (Imrie, 2000). The study participants may have been able to access their own adapted living spaces but often not that of friends, neighbours, or public venues. Neighbourhood excursions were central to the lives of the men because they afforded some of the few available opportunities to be outside of the confines of the home. The severely limited choices of living circumstances compounded by transport barriers constricted the men’s activities and limited their interactions to a bounded corner of the social space. The men responded by revising the boundaries of their lifeworlds or through strategies of resistance. Resistance to inadequate housing provisions took the form of rejecting available supportive living arrangements and staying in less than optimum circumstances in order to hold out for a location that met the participants’ social and spatial needs (rather than just their physical care needs). For example, Nick, who was living in a long-term care facility passed on the first available community space and waited another year for a location that provided proximity to his family as well as accessible opportunities to socialize with same age peers.

Place also had direct implications for the physical and mental health and safety of participants. Brian described a harrowing ordeal in his previous supportive housing unit where he was receiving attendant services that he described as ‘abusive’. As a result, he believed that his physical and mental health had suffered. He became depressed and lost a considerable amount of weight. He worried that he was going to ‘get sick’ and often wondered if he ‘was going to get to the morning’. He compared this to his current situation in a new supportive housing environment:

BG: After it was resolved did your depression get better?
Brian: Ya, I felt healthy, because people said to me ‘you look better, much better than before’.
BG: Really. In what way?
Brian: Just ‘cause I was healthier. Colour back. I didn’t really look too bad. Just colour and I guess I was happy. I guess not so stressed out. Knowing I was going to get up in the morning.

Brian’s story demonstrates the interrelatedness of socio-material places with emotional and physical health. Participants, who could not or chose not to live with their parents, often had little real choice in alternative living arrangements. Brian, for example, had to endure months of bureaucratic review and enlist the help of community advocates before he was able to move.

Revealed in the men’s stories are the processes through which techno-body-subjects are constituted through interactions with/in social spaces and experience multiple forms of material, social, and symbolic marginalization. This was evident in the myriad ways that the men’s techno-bodies were negatively marked and marginalized across most social spaces. Across their accounts were stories of being ‘othered’, either through direct expressions of being singled out or stared at, in their internalizations that were expressed in wishes for a ‘cybernetic body’, in all of the ways they identified themselves as shy, or in all of the ways their bodies were excluded from various locales because of mobility or other socio-material barriers.
The material, social, and symbolic limitations faced by men with DMD centre around the techno-body located in a social world that has no (good) place for it. Thus, technologies can be enabling and constraining, in both material and cultural ways. Access and mobility are a function of the way technology is organized, and the fit between bodily capacities and the organization of space and time (Freund, 2001). A space may be physically accessible but nevertheless may be experienced as exclusionary. Ventilator-users may not only be limited by material barriers; they may also be stigmatized because their technological baggage assigns to them a social meaning. Technology and place construct bodies and bodily possibilities, inseparable from the self. Individuals do exercise agency, but how this is expressed is constituted through their personal histories and the dynamic social processes of the wider social order and their individual local environments. The men restructured their activities and spaces as they worked to maintain or redefine their lives, goals, and priorities.

In emphasizing the socio-spatial isolation of the men, we do not intend to suggest that society has done nothing to address the marginalization of disabled people. Much progress has been made in the last three decades to remove barriers and work towards more inclusive communities (see Golledge & Stimson, 1997, pp. 492–498; Bickenbach, 2001). In the study we identified a number of social enablers including available but limited publicly funded supportive care, available but limited housing options outside of family homes, subsidized assistive technologies that facilitated mobility and augmented function, and opportunities for social engagement through organized wheelchair hockey. Nevertheless, the data not only suggest the need for more to be done in these areas, but also illuminate the complex intertwining of bodies, technologies, and place in mediating the material and cultural production of disabilities and exclusion.

**Implications**

We have discussed the interrelationship between bodies, technologies, and places, and proposed the ‘techno-body-subject in situ’ as a conceptual tool for considering the complexity of the disablement process for those with ‘extraordinary’ techno-bodies. In drawing from the accounts of men with DMD, we were particularly interested in demonstrating the need for conceptualizing this interrelationship in disability research and policy, but we expect the ideas to have broader applicability as well. While focusing on illuminating how medical devices can simultaneously address and produce or exacerbate disabilities, we located this discussion within a general notion of how technologies, bodies, and places interactively mediate individual experiences and perception and are implicated in the re/production of subjects. Our approach is in no way meant to be exhaustive but can be used as a conceptual tool for further inquiry by retaining the emancipatory goals of the social model and its focus on power relations while shifting the focus away from social construction in isolation to a consideration of the interplay between disabilities, bodies, technologies, and places.

In addition, this work highlights how critical social science approaches to the theorization of places, bodies, and technologies can contribute to bioethics research. There is an extensive bioethics literature that discusses ‘quality of life’ issues and the ethics of extending life through ventilation, but little of this work has examined how
prevailing social organization mediates the lives and experiences of actual ventilator-users. Amongst medical technologies, the ventilator is imbued with social meaning and remains a symbol of ‘extraordinary measures’ in health care. It is most often the machine that one envisions when speaking of ‘pulling the plug’ and thus has been linked with discussions of quality of life and euthanasia in public discourse (Longmore, 1991; Gray, 2002). Ventilation is associated with intensive care units, death and dying, and debates around offering or withdrawing ‘futile’ treatments. By and large, discussions of the ethics of ventilation have been focused on arguments regarding whether or not an individual can enjoy a good quality of life when ‘suffering’ from such significant impairment and/or whether these technologies should be made available to ‘patients’ (Purtilo, 1986; Miller et al., 1990; Bach & Barnett, 1994). These arguments are rooted in mainstream North American neo-liberal values and a bioethics that emphasizes autonomy, rights, and reasoning from abstract principles. While the debate has been valuable in challenging health professionals’ assumptions and has improved disclosure practices regarding ventilation (Gibson, 2001; American Thoracic Society, 2004), the discussion nevertheless has focused primarily on medical practices to the exclusion of larger social justice issues encountered by ventilator-users.

The focus on medical decision-making is at least in part related to how ethical problems surrounding medical technologies are generated and theorized. Frameworks that focus on the individual rights of a universalized subject fail to engage in the particularized lived experiences of groups and individuals that would likely generate different sets of questions. Technologically dependent persons and their real life experiences are largely invisible in discourses of medical technologies although they are members of the human community whose numbers continue to grow. We suggest there is pressing need to investigate the processes of exclusion and marginalization that they are subject to in their daily lives. This requires at least a rethinking of so-called ‘extraordinary measures’ that in the daily practices of technology-users have been recontextualized as both mundane and stigmatizing because they are not under medical control in intensive care units.

Another tendency is to reduce the problems of social marginalization to questions of distribution of scarce resources. Marginalization, however, as we have attempted to demonstrate, is more than a matter of material exclusion because of its multi-dimensional nature. Cultural or symbolic exclusion contributes to disablement through processes whereby persons are rendered invisible via the representational, communicative, and interpretative practices of a dominant social order (Fraser, 1995). Recent work in moral and political philosophy has reconsidered distributive questions through a lens of the ‘politics of difference’ and the social and cultural non-recognition that affects marginalized groups (Young, 1990; Taylor, 1994; Fraser, 1995). Fraser, in her work on the ‘redistribution-recognition dilemma’, proposes an approach to social justice that recognizes the mutual intertwining of economic and cultural injustices:

Even the most material economic institutions have a constitutive, irreducible cultural dimension; they are shot through with significations and norms. Conversely, even the most discursive cultural practices have a constitutive,
irreducible political–economic dimension; they are underpinned by material supports. Thus, far from occupying two airtight separate spheres, economic injustice and cultural injustice are usually interimbriated so as to reinforce one another dialectically. (Fraser, 1995, p. 72)

In outlining the relationship between these two forms of injustice, Fraser’s ideas reinforce the need for a disability ethics that considers not only socio-structural barriers but also the cultural and symbolic exclusion that is written onto the social landscape and the bodies of citizens. These are complex issues that involve a more thorough analysis than we have space for here. As a point of departure, we nevertheless suggest that complex problems of scarce resources must be considered within a larger social justice framework that includes the interrelationship between economic and cultural marginalization.

Ethical approaches that borrow from the social sciences may be useful in illuminating cultural marginalization in relation to medical technologies and disabled persons. As Kelly (2003) notes, ‘mainstream’ bioethics particularly in North America, tends to universalize the subject of rights, both as agents and objects of power. Along with others (Sherwin, 1998; Hedgecoe, 2004; Peter & Liaschenko, 2004), she has critiqued the universalizing tendency of this tradition and called for a bioethics that engages with the lived worlds of diversely constituted and situated social subjects. Such an ethics particularizes experiences and local intersubjectivities in social spaces where they are produced and reproduced. This provides a way to examine how exclusionary organization is constitutive of individual subjectivities and practices. Bioethical theory can be enriched by accounting for body-subjects as users, inhabitants, creators, and signifiers of technologies, places, and spaces. By doing so, bioethical inquiry attends to the complex functioning of power built into systems that can perpetuate social injustice. In our study, we saw how participants were excluded not only by their bodily limits but also by the ways in which policies, physical barriers, and negative representations of their techno-bodies were implicated in their social positionings.

In this paper we have presented a conceptualization of the interrelatedness of bodies, technologies, and socio-material places drawing from case studies of men with DMD as examples of persons with extraordinary techno-bodies. Our purpose was to provide a conceptual tool that incorporates a consideration of the ‘techno-body’ for exploring the mechanisms by which relations of domination, exclusion, or marginalization prevail. More work is needed to explore these relationships with various populations who rely on medical technologies and devices, and across different social and geographical spaces.

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