The power of power wheelchairs: Mobility choices of community-dwelling, older adults

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Abstract

Background—Power wheelchairs are purported to have a positive effect on health, occupation, and quality of life. However, there is limited knowledge about what factors shape power wheelchair use decisions.

Aims/Objectives—A study was undertaken to understand the mobility choices of community-dwelling, power wheelchair users.

Methods—A series of semi-structured qualitative interviews was conducted with 13 older adult power wheelchair users. Participants were interviewed at enrollment and four months later. Data analysis was informed by Bourdieu's theoretical constructs of habitus, capital, and field.

Results—Three main styles of power wheelchair use were identified: reluctant use, strategic use and essential use, and each type is illustrated using an aggregate case study.

Conclusion/Significance—These findings highlight the need to alter the power relationship that exists between prescribers and device users and to effect policy changes that enable people with physical impairments to make as wide a range of mobility choices as possible.

Keywords

Bourdieu; accessibility; participation; power mobility; electric wheelchair; qualitative

Mobility limitations affect one-third of older adults in the United States (1). Not surprisingly, they are the fastest growing and largest demographic of power wheelchair users (2). Many benefits have been attributed to the receipt of power wheelchairs. Quantitative studies have found power wheelchair use to be associated with improved mobility, social participation and quality of life, and decreased pain and discomfort (3). Specifically, users have reported that power wheelchairs facilitate a variety of activities including shopping, medical appointments, visiting family and friends, and attending community events (4).

Fewer studies have explored older adults' experiences of power mobility. Some studies have described participant experiences chronologically prior to and immediately after receiving a

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Declaration of Interest

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power wheelchair (5, 6). One qualitative study focused exclusively on the benefits of power wheelchairs in enabling social participation and role performance (5), whereas other research has described power wheelchairs as a mixed blessing in terms of accessibility issues and stigma that users may experience (4,6,7). For example, the size and programming of the devices may make them difficult to maneuver, which can precipitate accidents that damage property or cause personal injury (5, 8). Furthermore, some homes and public buildings may be inaccessible to wheelchair users, and power wheelchairs may necessitate expensive home and vehicle modifications (7). Funding policies also dramatically affect the equipment that users can obtain. For example, in British Columbia, Canada, where this study took place, public funding for devices is extremely limited and tightly controlled.

Little is known about how older adult, power wheelchair users make decisions about device use. In a study by S. Evans et al. (4), three of the 17 participants reported never using their power wheelchairs, and nine of the participants were infrequent users. The researchers offered only limited explanations for these findings. To examine the power mobility choices of older adults in a more nuanced way and identify different styles of power mobility, the current study employed interviews with a heterogeneous group of power mobility users.

This study was informed by Bourdieu's (9) theory of practice with its interrelated constructs of field, capital and habitus. Fields are social microcosms; each field has its own implicit rules that specify how it is governed. These fields are subsumed within the "field of power," which is a macro level space that includes society as a whole (10). Although fields are often considered virtual spaces, some fields, like homes and businesses also represent physical places. Capital can have either material (e.g., economic) or immaterial forms (e.g., symbolic or social), which can be transformed into power at different rates of conversion (11). Physical ability is a frequently unacknowledged form of capital that is required in a world that has been constructed to suit those with able bodies (12). Habitus refers to the dispositions and tendencies that agents in a particular field acquire over time, and that provide them with the tools to compete in the fields they occupy (9). "Habitus is an endless capacity to engender products—thoughts, perceptions, expressions, actions – whose limits are set by the historically and socially situated conditions of its production" (9, p95). In this way, habitus shapes choices—discouraging unpredictable novelty while allowing conditional freedom. The combination of habitus, capital and field combine to produce social practices (11). Those who are most dominated are those "with habitus least well suited for the contestations specific to that field" (13, p694).

Material and Methods

Interpretive description was the methodology used in this study (14). This is an inductive approach that enables phenomenon to be explored in way that can inform clinical understanding. Qualitative interviews were the primary method of data collection. The study was approved by the local research ethics board.

Recruitment

Participants were part of a larger, quantitative study on power wheelchair use (reference omitted for blinding). Participants were recruited via the study website and through posters

and newsletter notices. To be included in the study, participants needed to be 50 years of age or older, proficient in English, able to use a power wheelchair independently, and have no cognitive impairment. Individuals who fit the criteria were also invited to participate by third party recruiters including occupational therapists, physical therapists, and wheelchair equipment vendors.

Data Collection

Two open-ended audiotaped interviews were conducted with each participant. Interviews occurred at enrollment and four months later to examine any changes that may have occurred over that period and to follow-up on the topics previously discussed. Interviews ranged from 45 minutes to two hours in length and took place at a location of the participants' choice: 20 interviews were conducted at participants' homes and six at a research facility. Interviews were conducted by the first, third and fourth authors. Interviewers included a wheelchair prescriber who was an experienced qualitative researcher and two Masters of Occupational Therapy students who were trained to conduct qualitative interviews. Data were collected from November 2010 until July 2012.

Interviews were based on two semi-structured interview guides. Topics for the first round of interviews included wheelchair use, participation in activities, mobility challenges, wheelchair features, changes in the wheelchair and user over time, and reactions to wheelchair use. Examples of questions asked included, "How do you use your wheelchair on a daily basis?" and, "What difficulties do you encounter when using your chair?" The interview guide for the second interviews included questions about changes that occurred during the four months between interviews and topics that emerged during the preliminary interviews. Novel topics emerging from the first round of interviews, such as training received and the occurrence of accidents, were integrated into the interview guides for subsequent interviews. Sociodemographic information (e.g., age, sex, income) was collected during the initial interview. After each interview, field notes were taken denoting the interview environment, content, perceived impact of the researcher on the participant and any technological difficulties. For consistency, participants had the same interviewer for each interview.

Analysis

We did not employ Bourdieu's concepts prescriptively but as a framework to derive inductive meanings from the data. These data were analyzed to explore mobility choices and identify different styles of power mobility use among participants. In this case, style refers not just to frequency and patterns of use, but also participants' perceptions about their devices. Analysis was ongoing throughout the data collection process. Each interview was transcribed verbatim. Interviewers recorded reflective notes pertaining to ideas about the codes and their relationships to help understand and organize the data. The first author listened to the recorded transcripts and subsequently reviewed all of the transcripts and reflective notes to understand the mobility choices of these wheelchair users. Through collaborative discussions with the other authors, three main styles of power wheelchair use were identified (i.e., reluctant use, strategic use and essential use). With reluctant use, power mobility was not used habitually because it was an ineffective form of capital. With strategic

use, power mobility was used when it was most advantageous. With essential use, power mobility use became habitual as it represented the most viable option for independent mobility. Each style was illustrated through the use of aggregate case studies in which data from multiple participants were amalgamated. To create each archetypal case study, we drew on narratives that were common among participants in each typology and illustrated these with direct quotes from participants. We selected the diagnosis, age and gender for each case study, based on the characteristics of participants in each typology and a desire for verisimilitude (e.g., we decided that a person with a diagnosis of multiple sclerosis would best illustrate essential use and since that diagnosis is much more common among women we made that case study female).

Results

Participants included 7 men and 6 women with a mean age of 60 and a mean of 10 years of experience with a power wheelchair. All participants were community dwelling Caucasians who lived in a large coastal city in British Columbia. Only four reported receiving any formal power mobility training. Sociodemographic information and wheelchair-related data about the participants in each typology are provided in Table 1. On average, reluctant users were younger and strategic users were older. The majority of reluctant and essential users had spinal cord injuries, whereas the majority of strategic users had other neurological conditions.

Reluctant use

Joseph is 60-years-old with a C7 spinal cord injury. He was injured riding his motorcycle 30 years ago. He is currently on long-term disability support and has additional health insurance provided through his former employment, which covers most of his equipment needs. He is having increasing difficulty propelling his manual wheelchair. He was prescribed an electric wheelchair six months ago, but it required a succession of modifications, so only in the last few months has it been completely set up. He reports he was provided only minimal training on how to use the device. He prefers to use his manual wheelchair inside his home, because he has more “finesse” with it as its use has become habitual. He only uses his power chair occasionally outside the home, because there are many things that discourage his use of power mobility.

One major environmental issue is transportation. Currently, he has a van that is accessible for a manual wheelchair. Unfortunately, it is unable to accommodate his power chair, and a new van would cost between \$60,000 – 80,000 (Canadian). Unfortunately, he lacks the capital necessary to buy a new van so he is unable to exploit the power wheelchair that he has received. Therefore, he needs to rely on public transportation, or to use the power chair as a form of transportation to get from place to place, but weather is a determining factor. He would never use his electric wheelchair when it is snowing, because as he points out, “Snow removal is very haphazard in here and [my power chair] handles like a curling rock in snow.” Cold, rainy weather can also be a deterrent, as he has trouble regulating his body temperature. When it rains, he covers the controller with a plastic bag to prevent it from getting wet.

In terms of habitus, power wheelchairs also provide a completely different kinesthetic experience. He finds there is a distinction between “driving” a power wheelchair and propelling/pushing/wheeling a manual chair as he considers the latter more active and he enjoys the sensation of rolling downhill. Furthermore, when his wife is with him, she is able to help get him up any inclines in his manual chair.

Regardless of the type of wheelchair he uses, Joseph encounters a variety of barriers in the physical fields that he enters. Although he generally finds the city to be very accessible, there are some places where a lack of curb cuts is problematic: “[At one intersection], there’s a [curb cut] only going one way...so to go north...you have to go out into the traffic and then get around the other side to be able to cross the street.” Although most businesses he frequents are accessible, some provide only alternative access. For example, when Joseph inquired about accessibility at a local theatre, he was told that instead of entering through the front door, “all you have to do is go down the lane, past the dumpsters, and we’ll let you in by the door by the screen.” Uneven sidewalks are also a concern for Joseph, because they trigger spasticity in his leg. “Sometimes the sidewalks are in rough shape. They’ve got lumps and bumps and everything in it. So my leg goes nuts and I feel like I’m falling down.” For this reason he has developed an intimate knowledge of his immediate surroundings, “I know every nick and crack. I know every place to take it slow.”

Strategic use

Margaret is a 62-year-old woman who had a stroke two years ago. Initially she had left-sided neglect (ignoring things in her left visual field) and was frustrated by her therapist’s refusal to let her try a power wheelchair while she was in the rehabilitation hospital. On discharge, she was able to walk short distances independently using a quad cane, and was given a manual wheelchair that she propelled with one hand and one leg. As her left-sided neglect resolved, she requested re-assessment for a power wheelchair. Although she was deemed “appropriate” for a power wheelchair by an occupational therapist, she needed to file an appeal with the [government] ministry, as they normally only fund one mobility device every five years. “So I appealed saying, ‘You know this isn’t a choice for me. I absolutely have to have one.’ I had letters from the occupational therapist and from the doctor, from everybody but the whole process still took over one year.” She only qualified for government funding for her wheelchair because she had limited income, was under 65 years of age and the power chair was deemed medically necessary for mobility.

She was unable to return to her multi-story home, because she could not use the stairs within this field. Therefore, she was discharged to a seniors’ lodge and eventually moved into social housing. Although the housing complex has wheelchair accessible suites, their policy of not letting suites remain vacant means that most are currently occupied by ambulatory residents and she ended up in an un-adapted suite.

In terms of her habitus, she describes how her skill driving a power wheelchair improved over time, “It’s gone from absolute terror to feeling pretty good. I’m now slowing down where I should and not so much where it’s ok. [...] But I’ve stuck at it and I’m getting much better at it without being terrified.” During the first interview, she indicated that she was comfortable using the city subway system, but was afraid to use the city bus system, because

of concerns about crowding. Prior to the second interview, she went for training from the transit authority on how to use the bus, which gave her the confidence she needed to start to use it regularly. By becoming proficient at using city buses, this greatly expanded the locations she could visit in her power wheelchair. In her housing complex, she sometimes attends activities using her cane, but if the activity is too popular, she will take her power wheelchair, because she feels safer and also knows she will have a place to sit.

Using her power wheelchair, Margaret encounters a variety of physical barriers. She notes her un-adapted apartment is “designed so poorly for [her] needs” that it is “a lot of work” just to accomplish daily tasks such as cooking. She also had difficulties getting the housing board to put grab bars in her shower and expressed concern, “If I fall...I would be grabbing the shower curtain and the rod would come with me.” When she does encounter stores that are not accessible, she tends to be acquiescent: “Well that’s just life, right? Life is not going to be perfect; stores aren’t going to be perfect. I mean some smaller store is not going to change their store just because of me. I just accept that, that’s the way it is so you just don’t go there.”

Ironically, despite the size of her power wheelchair, one of the biggest issues that Margaret encounters is not being seen. Cars are a constant threat when crossing intersections as she has experienced several near misses. Similarly, Margaret sometimes feels invisible in her power wheelchair in social settings, “It’s been a big adjustment because people look right over you and just discount you.” Otherwise, Margaret is generally pleased by the assistance that she is offered in public settings: “People are very kind you know. You sit there at a door looking for a while, and people say, ‘Do you want me to open that door?’ They are all so helpful.” One of the big adjustments for her, however, was learning how to ask for help from strangers, which she found difficult initially.

Essential use

Linda is a 69-year-old who was diagnosed with multiple sclerosis 25 years ago. She lives with her husband, in a home that has been adapted for wheelchair use by the installation of an elevator, and bathroom and kitchen renovations. Her condition has slowly deteriorated over time. Initially she walked with a cane, and progressed to a scooter. One year ago, she had to stop using her scooter, because she needed more supportive seating. With the aid of an assistant, she uses a mechanical lift to get in and out of her wheelchair. Funding for her power wheelchair was mostly covered by her private health insurance. Based on the recommendation of her occupational therapist, she ordered a power wheelchair with a feature, which allows her to tilt her whole seat backwards. Her power wheelchair is a critical form of capital for her. She loves being able to move independently in her power chair as she points out, “Thank God wheels are made to roll. I love the movement, I just love it.” She found learning to drive the power wheelchair was a learning curve, because it was different from her scooter. “It was like changing your comfort zone [...] You’re so aware of the scooter and it, its perimeter and its function and its idiosyncrasies, its beeps and its grinds and what it can do and what it can’t do.” But now in the power wheelchair she reports, “I don’t even think about driving it, it just goes where I want it to go.” She feels like she has a synergistic relationship with her wheelchair, as she indicates, “It’s part of your body

actually. [...] It's part of your sense of who you are." In this regard, the wheelchair is part of what she describes as her personal space and its use has become completely habitual. To increase its utility she has customized the chair by adding a cup holder, wheelchair bags, lights for nighttime use, and seasonal decorations. In this way, her power-chair is a continually evolving project, which increases in value over time. Originally, she found the need to switch to a power wheelchair was disheartening, because she thought, "if you go into a power chair you're kind of giving up but after a while I kind of realized it was actually good because it gave me more independence". She still had an ongoing concern about the stigma associated with power wheelchair use, because she felt her scooter made her feel less disabled.

Malfunctions are a serious concern for Linda. For example, when her tilt-in-space feature stopped working it made it more dangerous for her to negotiate curb cuts, as she worried her foot pedals might catch. She was also concerned about the potential for a complete breakdown, because then she would be stuck at home and dependent on others for mobility, "I couldn't get out of the house without it". Conversely, she could also become stranded away from home.

Discussion

This study identified three styles of power mobility use. In each instance, power mobility represents a distinct form of capital. Its effectiveness as a form of capital varies according to how well it is adapted to the 1) habitus of the user (e.g., customization to suit the individual's abilities, needs and preferences) and 2) fields in which it is used (e.g., the physical and social environment, the climatic conditions). Given the relatively static nature of these devices and the changing demands of the users and their fields, however, the worth of these devices varies considerably in any given moment for each user. In this regard, there is generally an internal logic to the mobility choices of individual electric wheelchair users, who, depending on their abilities, use the devices in different ways in different situations.

Some power wheelchair users are reluctant to use their devices because the disadvantages associated with power wheelchair use out-weigh the benefits. Long-time manual wheelchair users can become very skilled using these devices – to the point where their use of the devices feels completely natural (15). In this regard, manual wheelchairs may represent what Le Corbusier (16) refers to as "limb-objects" in that they act as extensions of the body, and awareness of them fades from consciousness in much the same way that corporality is frequently ignored by those who are healthy (17). Among reluctant users, power mobility may disrupt the sense of hybridization that experienced manual wheelchairs may have achieved with their mobility devices. Having spent considerable time to appropriate their manual wheelchairs as a form of capital, they may be hesitant to adopt power mobility. Power wheelchair use may also be ultimately less kinesthetically pleasing, as it denies them the opportunity to enjoy the excitement associated with rolling effortlessly downhill. Similar kinesthetic experiences have been described among road cyclists whose sense of self is hybridized with that of their bicycles (18). Furthermore, manual wheelchairs not only provide mobility, but they also convey the message that users are active agents within their

environments. Although naturalness is sometimes conflated with ease (11), in this case, the effort involved in manual wheelchair propulsion is actually part of their capital.

A range of contextual factors may discourage power mobility use. Users who rely on public funding or lack financial resources may not have access to the most appropriate devices and prescription services. A lack of programs to fund modifications to private vehicles to accommodate power wheelchairs may be a further disincentive, since a power wheelchair may preclude the use of an automobile, which is both an instrumental means of transportation and a social symbol of status and power (19). Thus, power mobility may ultimately restrict users' mobility, thereby contributing to their marginalization in the field of power.

Strategic users employ power mobility intermittently for a variety reasons. They may use a power wheelchair to enable them to go further and to do more things independently, as has been previously documented (3,6). Strategic users also wanted to avoid the potential of deconditioning. They worried that using power wheelchairs in the short-term, might negatively affect their physical function in the long-term. Losing the capacity (i.e., corporeal capital) to ambulate or to transfer has severe consequences given the low level of assistance that is usually available for those living in the community in many countries. Assistance provided by others may come at a financial or emotional cost, and is not always available when desired or necessary. Policies that provide funding for only one primary device, however, may limit the tactical mobility choices power wheelchair users can make.

The environmental and social barriers that essential and to a lesser extent strategic users experienced sometimes excluded them from certain fields and restricted their occupational engagement. Because power wheelchairs are unable to perform "wheelies", a lack of curb cuts can make accessing certain fields difficult and sometimes impossible, which Imrie (20) has described as "design apartheid." Ironically, despite the perceived conspicuousness of these devices, users could be overlooked when using powered mobility—a disappearance from the perspective of others who sometimes treated them as invisible "non-persons" (21). Problems with accessibility are frequently attributed to the device, rather than to the environment, which obscures how these barriers are socially constructed. Token efforts to improve accessibility (e.g., offering a backdoor means of entry) may effectively stigmatize power wheelchair users. This marginal accessibility may allow them to enter some spaces, but does not make these locations into places where they feel they belong. Adopting the principles of universal design would be an inclusive strategy to promote changes to the physical environment, as they are intended to find ways to enable as many people as possible, regardless of their abilities. Discrimination may disrupt the sense of hybridization that users have developed with their devices. Users' pre-existing attitudes and prejudices may also make adoption of power wheelchairs more difficult. In this regard, they may experience "habitus mis-match" as their pre-existing patterns of behavior and thought may not be congruent with the demands of the current fields that they occupy (22)

Although power mobility is the only means of independent mobility for essential users, they frequently customize their wheelchairs to meet their needs for comfort and function or to reflect their personalities. In the latter case, rather than being an object to be dismissed from

consciousness, power wheelchairs, as a form of capital, become a focus of attention, in much the same way the body could be considered as a project that is “worked at and accomplished as part of an individual’s self-identity” (23, p4), for example, body building or tattooing.

As a sole means of independent mobility, essential power mobility use represented a kind of habitus that sometimes required other related changes to habitus. Although learning how to ask for help from strangers or to get device approval from a prescriber may seem relatively innocuous, it reflects a shift in power relations, which may go unrecognized. Agents in a given field may magnanimously appear to share capital that they have, but, in doing so, they become dominant in that relationship as Bourdieu (24, p94) describes: “Man [sic] possesses in order to give, but he also possesses by giving.”

As users become comfortable with power mobility, they may incorporate these devices into their body schemas (25), and a positive feedback loop may be established. As power mobility is used, the user’s skills may grow and with enhanced skills, powered mobility becomes more useful. With barriers to use, however, the skills needed to use a power wheelchair may not become habitual.

It would seem intuitive that mobility choices should be enabled rather than restricted, but in practice, the converse appears to be promoted. Access to power wheelchairs is tightly controlled through private health insurance and government funding, which excludes many who would benefit from their use. Furthermore, because agencies generally fund only one primary device, if a back-up manual wheelchair is provided it will frequently be less well adapted to the individual and his or her environment. This may discourage some wheeled mobility users from obtaining a power wheelchair. The low number of power wheelchair users who reported formal training is in keeping with findings from other studies (26). Limited training may prevent potential users from becoming comfortable operating these devices and prevent current users from developing proficiency. All of these factors tend to limit the strategic use of powered mobility, which may restrict rather than enable users’ mobility and occupational engagement.

Several potential clinical, policy and methodological implications emanate from this study. As prescribers are often complicit with the administration of discriminatory government funding policies, they may represent a barrier to attaining needed mobility resources (27). This suggests that there needs to be a re-alignment of the power relationship that exists between prescribers and device users, so that more collaborative relationships can be fostered, congruent with our commitment to client-centred practice. This shift would oblige prescribers and their professional organizations to lobby for changes in the way that needed devices are funded and provided. To reduce the prevalence of reluctant use generally and essential use specifically due to overuse injuries, power mobility add-ons such as SmartDrive™, e.Fix™ or power-assisted wheels might be considered. To facilitate hybridization, it may be beneficial to look at novel, less prescriber-centred ways to provide device training and to support use, perhaps through peer training groups or improved electronic resources. In terms of policy, it is important to consider how those with able bodies benefit from the ways society is set up to accommodate them including the

significant investments in public infrastructures that support those who can walk, cycle or drive (28).

The use of Bourdieu's theory of practice was helpful as a framework to understand how electric wheelchair users make mobility choices and this research extends his work in novel ways. Although fields are often considered as virtual spaces, this research found it was also informative to study fields as concrete physical spaces, which are socially constructed. Although capital is usually conceptualized in a static way, this study emphasizes how its value can fluctuate, depending on a variety of personal and environmental factors. Furthermore, in some circumstances, electric wheelchairs may be more disabling than other forms of mobility and, in these cases, they might be regarded as a negative form of capital.

Several strengths and limitations of the study and areas for future research should be noted. The heterogeneity of the sample and the use of repeated interviews were strengths of the study. However, the small number of participants, from a specific geographical region in British Columbia, Canada may limit the transferability of the findings to other settings and other populations. For example, problems with snow removal, poorly designed or absent sidewalks, and lack of curb cuts will be greatly magnified among those living in rural areas. Exploring mobility choices among individuals from different ethnicities and cultural backgrounds would broaden our understanding. Studies that explore the financial, emotional, physical, and social benefits of policies that support mobility choices among those with disabilities are also needed to contest neoliberal governmental funding guidelines. If such research was accompanied by a commitment to action, those who are presently disabled by society could attain access to those mobility devices and environmental changes that would enable their equitable participation.

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Table 1

Sociodemographic characteristics of power wheelchair users

Variable	Reluctant (n=3)	Strategic (n=5)	Essential (n=5)
Age (years) (<i>M</i> ^a)	56	62	59
Female (n ^b)	1	4	1
Marital status (n)			
Currently married/common law	1	2	2
Divorced/separated		2	2
Single/Widowed	2	1	1
Reason for power wheelchair use (n)			
Spinal cord injury	2		3
Amputation		1	
Neurological (e.g., stroke, MS)		3	1
Other	1	1	1
Income \$1000s (<i>M</i>)	35	38	48
Power wheelchair use (Years) (<i>M</i>)	11	1	12
Formal Power mobility training (yes)		2	2
Manual wheelchair use prior to power wheelchair use (yes)	3	5	3

^a *M*= mean^b n= number