

EXPERIENCES OF CANADIAN POWER MOBILITY USERS OVER TIME

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OVERVIEW

- Background
- Objectives
- Theoretical Foundation
- Methods
- Results/Discussion
- Conclusion

BACKGROUND

PREVALENCE OF POWER MOBILITY

- @ 297,000 individuals used power mobility in the US in 1995 (Kaye, Hang & LaPlante, 2000).
- From 1999 and 2003 there was a 300% increase in the number of power mobility reimbursements made through Medicare, up from 55,000 to 159,000 annually (Dicianno & Tovey, 2007).



BENEFITS OF POWER MOBILITY

Power mobility use has been associated with:

- increased mobility (Auger et al, 2008; Mortenson et al., in press),
- enhanced participation in daily activities (Brandt, Iwarsson and Stahle, 2004; Evans 2000; Mortenson et al. 2005),
- decreased pain and discomfort and an improved quality of life (Davies, De Souza, Frank, 2003; Evans, Frank, Neophytou, De Souza, 2007).



PROBLEMS WITH ACCESS

- Expense
- Age, income or ability-related criteria may restrict access to funding programs.
- In British Columbia (BC), low income individuals with disabilities are only eligible for government funding for devices until the age of 65.
- Must be medically necessary for mobility.



PROBLEMS WITH ACCESS

- In contrast, in Quebec, everyone is eligible if they meet certain disability criteria
 - i.e., inability to propel a manual chair to perform daily activities.



WHEELCHAIR-RELATED ISSUES

- Accessibility problems (McClain et al. 2002; Meyers et al.; 2002; Mortenson et al., 2005)
- Home adaptation may be expensive
- Safety is a serious concern (Mortenson et al., 2005; 2006)
- Accidents may have lethal consequences



WHEELCHAIR-RELATED ISSUES

- Discrimination (McClain et al. 2002; Meyers et al.; 2002; Mortenson et al., 2005; Papadimitriou, 2008)
- Stigma (Cahill & Eggleston, 1995; Goffman, 1963)
 - Open persons (Goffman, 1965)
 - Non-persons (Goffman, 1959)



WHEELCHAIR ADAPTATION

- Over time, wheelchairs can come become part of a user's identity (Papadimitriou, 2008)
- Drawing on the work of Leder (1990), Winance (2006) suggested that
 - 1) during the trial process, the wheelchair becomes part of the user's body, and
 - 2) ability can only be enabled when the device fades from awareness.

PURPOSE

PURPOSE

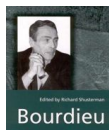
Overall: What are the experiences of older adult power wheelchair users over time?

Specifically :

- How do users adapt to power wheelchair use?
- How does power wheelchair use affect participation in occupations over time?
- What environmental barriers and facilitators do users encounter?

THEORETICAL FOUNDATION

FIELD



“Relatively autonomous social microcosms [which exhibit] their own distinctive structures and dynamics.” (Emirbayer & Williams, 2005, p. 690).

HABITUS

- Enduring patterns of behavior
- Distinguish individuals (in terms of social class, for example) and are also a means through which actions are produced. (Bourdieu, 1993)

CAPITAL

- Each field has its own rules that specify which forms of capital are sought by those within that field.
- Capital is not purely economic (can be cultural or symbolic, etc.)
- Physical capital (Edwards & Imrie, 2003)
- Can be converted from one form to another (Bourdieu, 1984).

METHODS

INTERVIEWS

- Plan to conduct 4 in-depth interviews overtime (enrollment, 4 months, 13 months, 25 months)
- Based on an evolving interview guide
 - How do you use your powerchair on a daily basis?
 - What difficulties do you encounter when using your powerchair?
 - How satisfied are you with your powerchair?



INTERVIEW NOTES

Recorded detailed notes about

- the setting of the interview,
- the participant ,
- initial impressions, and
- interactions between the participant and interviewer.



INCLUSION CRITERIA

- Power wheelchair user
- Proficient in English
- 50+
- Independent powerchair operator
- No cognitive impairments
- Volunteers from the larger quantitative study...

SETTINGS (FIELDS)

- Not prescriptive about living situation, i.e., institutional /community, single/ alone, working/retired.



TRANSCRIPTION/TRANSLATION

- All interviews were audio recorded and transcribed verbatim.
- French interviews are being translated into English by members of the research team.

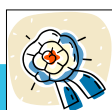
DATA ANALYSIS (HAMMERSLEY AND ATKINSON, 1995)

- Ongoing throughout the data collection
- Continually re-read initial transcripts and interview notes
- Developed an initial coding guide
- Altered this guide as new codes were identified and then recoded previous data
- Assembled the codes into sub-themes and these subthemes into main themes



TRUSTWORTHINESS

- Reflexivity (positioning and presence)
- Repeated interviews, multiple researchers, involved in data collection and analysis
- Member checking planned



RESULTS

PARTICIPANTS

Pseudonym	Age	Sex	Diagnosis	Mobility aid prior to PWC	Exp. (Y)
Angela	65	F	MS	Cane, walker, manual chair	10
Maria	54	F	MS	Scooter, manual wheelchair, walker	1
Nadya	52	F	Neurological	Walker, cane	5
Jane	62	F	Spinal bifida	Manual chair	10
Trevor	67	M	Paraplegia	Manual chair	7
Grant	54	M	MS	Scooter	7
Harold	53	M	Tetraplegia	Manual chair	12
Denis	55	M	Tetraplegia	None	30 +
Genevieve	57	F	Back problem	Cane	weeks
Juliet	72	F	Spina bifida	Manual chair	17
Philippe	51	M	Tetraplegia	None	30+
Charlie	66	M	Stroke	Manual chair/cane	weeks
Tom	55	M	Paraplegia	Manual chair	27
Beatrice	83	F	Amputations	Walker, cane, manual wheelchair	1

OBTAINING AND ADOPTING
POWER MOBILITY



PATHWAYS TO POWER

- Denis (55 year old with high spinal cord injury)
- Trevor (67 year old with paraplegia)
- Jane (62 year old with spina bifida)
- Many participants could select between various forms of mobility (cane, walker, manual, or power)

PATHWAYS TO POWER

- Participants who used different devices tended to have more physical capital than those who used power mobility exclusively.
- Enabled users to experience and to express different kinds of habitus in different settings.

FUNDING FOR POWER

Participants received their chairs through a variety of sources:

- private insurance,
- provincial programs, or
- personal funding.



NEGOTIATING

“When I ordered this chair I wanted solid inserts. Human resources, said we’re not going to buy them. They’d rather pay the eighty-five dollars [...] to get one of these flat tires fixed. [...] After multiple flat tires and stuff [...] I finally [...] phoned up human resources, I said, “I want solid inserts, yeah, okay. “ Well they saved themselves a lot of money [and I] don’t have to worry about flats.”

Trevor (67 year old with paraplegia)

FINANCIAL CAPITAL

- Those with means were better able to meet their needs with assistive technology: exchanging money for power
- Those that relied on government programs needed to negotiate with prescribers and funding agencies that had considerable discretionary power in these fields (Jörg, Boelje, & Schrijvers, 2005).
- Likely disadvantages those without suitable habitus

FACILITATING PARTICIPATION

“It makes everyday life things much easier”

-Angela (65 year old with MS)

PART OF YOUR BODY

“[My wheelchair]’s a huge part [of my identity...], it’s part of your body actually. [...]It’s part of your sense of who you are. And that’s what sometimes they [manufacturers/ prescribers] don’t take into consideration and then sometimes can’t understand why people reject chairs. It’s not the mechanics of the chair; it’s how you perceive that piece of machinery as being part of you. And how you see that part as an extension of your body.”

Harold (53 yr old with quadriplegia)

CYBORGS

DENIS: I jokingly refer to myself as a Cyborg but I don’t see myself that way, I refer to my chair as my iron horse. [...] It is a mobility device sure, it’s not part of my body although it is part of me in this, in my situation of being disabled.

Ben: The idea of the iron horse is unique because horses have personality . So it’s almost like you have a relationship with...

DENIS: Yes I, I would say so, yes, yes, it’s not a personal relationship as it is with an animal but this chair has its quirks and I’m familiar with them and I’m familiar with [...] how it turns and drives and all that so there is an interaction between you and the chair that [...] you adapt to.

(55 year old, with high spinal cord injury)



ADOPTION

- Harold and Denis exemplify different perceptions about the wheelchair.
- The former is more like Papadimitriou's concept of "enwheelment" whereas the latter is more like Le Corbusier's (trans., 1987) idea of 'limb-object' : an extension of the human body, like a chair, that is discrete from it.

LEARNING CURVES

"Learning to drive the wheelchair was a learning curve but now I don't even think about driving it, it just goes where I want it to go."

Grant (54 year old with MS)



FEELING AWKWARD

"I never use the electric wheelchair around home [...] I could [...] but it would be awkward. [...] I think it may be just mental, but I think I have more control over the manual chair, I can do more, I have more finesse. It probably is because I've never used the electric chair to do things consistently [...] day after day. I can see maybe in the future what will end up happening is I'll use the electric chair all the time. And I notice that I'm using it more and more now so I think it's best for me in terms of my stage of aging."

Jane (62 yr old with spina bifida)

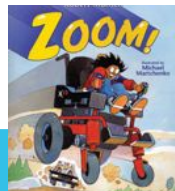
APPROPRIATING

- Jane and Grant's examples demonstrate Bourdieu's idea of "appropriation": making the use of acquired capital appear completely natural.
- Only for Grant could the full potential of his power wheelchair as means of mobility and a source of status be achieved.

KINAESTHETIC PLEASURE

"Thank God wheels are made to roll. I love the movement, I just love it."

Trevor (67 year old with paraplegia)



MASTERY

"It's just being moving. The feeling of movement. Overtaking people on the sidewalk. Small things like that. It's just the challenge of driving because there is a challenge but you don't think of it in a vehicle out on the highway but there is a feeling of getting from point A to B and being able to power myself."

Denis (55 year old, with high spinal cord injury)

KINAESTHETIC PLEASURE

- Power mobility was not merely functional, but also had a subjective dimension (means and ends).
- Likely allowed participants to demonstrate their mastery and to (re)experience the (pre-wheelchair) habitus of unencumbered movement.

RESISTING CHANGE

DENIS: I'm like an old dog like I don't like change. I had my first chair until the people that fixed it said we just can't fix this anymore and they kind of forced me to start looking for a new chair. So I've had this one since 1999 which is I've only used it for ten years. And I've encountered the same problems because they can't get parts for it so I'm in the process of getting a new chair now.

R: What's that transition like for you?

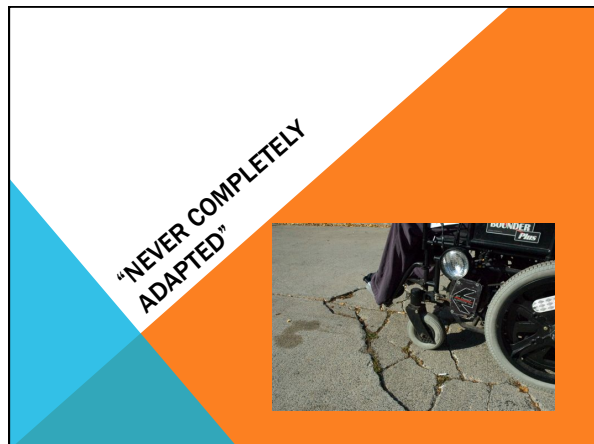
RESISTING CHANGE

DENIS: It's like changing your comfort zone [...] You're so aware of the chair 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. So I'm aware of having to learn the limiting idiosyncrasies of a new chair which might be an easy transition which this one was or it might be, it might, you know, take a little longer to feel comfortable like I do with this one.

(55 year old, with high spinal cord injury)

RESISTING CHANGE

- Understandable given the time taken to appropriate their current devices and potential for unanticipated problems with the adoption of new technologies (Rogers, 1995).
- Each assistive device represents a compromised choice that enables some habitus better than others (Lenker & Paquet, 2003).



ACCESSING

"Vancouver is the best place to be disabled because it is the most disabled friendly city in the world. It's just perfect. You know we have rules about curb cuts and access to public buildings and they don't have that in other places."

Angela (65 year old with MS)

ACCESSING

"You go down from one side of the street, then you cross to the other side, and there is no curb cut. So then you must go in traffic in the street to the next garage, but there is someone coming in front of you, he is cursing you, because you're on the street you are in his way, [and] the curb cuts for the garages are not made for the disabled so there are times where there is a lip 3 inches high."

-Genevieve (57 year old with back problems)

FIELDS

- Participants in Quebec experienced more barriers in the physical environment, which restricted their access to certain fields and affected their habitus.
- Changing feelings of ease with power mobility use to dis-"ease" (Leder, 1990)
- Excluding those with disabilities from certain places (Kitchin, 1998)

ACCESSIBILITY OVER TIME

"[I know 2 wheelchair users who were visiting Vancouver]. And they got on a bus downtown [...] and they were so enthralled to be on the bus they went several blocks [...] past their stop before they realized they'd gone too far, they were enjoying so much being on a city transit bus, that was 1992 which is still quite recent. And I don't like to compare this because I know a comparison isn't apt with the segregation [...] but you know, Rosa Parks couldn't sit at the front of the bus but she could still get on the bus where disabled people for years couldn't get on the bus. So, you know, it was the black movement and the women's movement and I think we've had a disabled movement with success in Canada."

Denis (55 year old, with high spinal cord injury)

CHANGES IN THE FIELD OF POWER

- Changes in the field of power in terms of the positioning of those who are disabled by society.

ACCESS

"The new [buildings are] more universally accessible whereas the older ones you're going to run into places where it's not. [...] That's the reality. [...] Some people get really choked about that. I go, "Well that's just life right, life's 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."

Harrold (60 year old with paraplegia)



DIFFERENT STRATEGIES

- Harold describes two possible reactions to problems with the built environment.
- His preferred strategy involves acceptance, whereas others reject these imposed limitations.
- Although understandable, his acceptance of the rules of the game (what Bourdieu describes as *doxa*) may contribute to reinforcement and reproduction of the *status quo* (Bourdieu, 1984).

WHEELCHAIR ENVIRONMENT FIT

"My [tilt] button isn't working. You need the [tilt] switch when you're heading to [town] because the hills are very steep and [...] if you can't tilt you're going to [fall] So make sure you put your seatbelt on and go a little slower [...]. There's some construction and stuff they're doing down there [...] and having to go around the back way...the side walk there is crappy. It's got lumps and bumps and everything in it. So you're going down the road and there's a driveway that you have to go at an angle [tilt] while you're going over. And it's bumpy. So my legs are going nuts and I feel like I'm falling down the ramp."

Maria (54 year old with MS)

WHEELCHAIR ENVIRONMENT FIT

- Given the unreliability of her wheelchair capital, and problems with the built environment (physical elements of the field of her community)
- Maria loses control over her legs, and is afraid of falling.
- Experiences which might encourage her to constrain her activities and further restrict her *habitus* in the future.

PEOPLE AS ENABLERS

"I am always amazed at how kind people are . In fact, at the bank where they have a button you press to get in and out if you want to and have mobility issues . People are always there to open the doors...they are so kind. It is so amazing."

Angela (65 year old with MS)

PEOPLE AS BARRIERS

"Everyone has got these backpacks on and they're got these stupid ear plugs in their ears and they're standing out in the middle of the bloody sidewalk there and [...], there's a line up there waiting for the bus. Well I want to use the sidewalk, I've got to get through."

Trevor (67 year old with paraplegia)

BEING SEEN

"I'm tall and I'm used to being seen and in a chair you don't get seen. People, they don't see you for your height. [...] It's been a big adjustment because [...] people look right over you and just discount you. [...] I've been trying to do things like [...] getting eye contact; not letting people just ignore me but [...] it's part of the post stroke transition. It's a piss off. Your life changes so quickly and you're not just not prepared for it."

Charlie (66 year old with Stroke)

INVISIBILITY

- Non-persons (Goffman, 1959)
- Sitting posture seemed to negatively influence participant's social positioning, as they were discounted by others because of their appearance (Bourdieu 1984).



BEING SEEN

I'm in the middle of a green walk [light at an] intersection [and] somebody is on their cell phone blah, blah, blah and they're looking this way to make sure no traffic is coming from the left, go around the corner and I'm right there. Three times [they came] that close to running over me.

Trevor (67 year old with paraplegia)



AESTHETICS

"Something that looks like it isn't put together with a lot of pieces, I want a self-contained unit. Some chairs have wider bases and they'll just build whatever you want, [...] So you could have quite a hodge-podge looking chair."

Denis (55 year old with a high spinal cord injury)



AESTHETICS

"I guess [the chair reflects my personality] . It's different. [When I go to the rehab hospital] Everybody in a power chair [...]says, "wow, where did you get that done?"

Trevor (67 year old with a high spinal cord injury)



WHEELCHAIR WORK

- Rather than trying to make his wheelchair become part of the background, Trevor actively tried to make it visible.
- Reminiscent of Schilling's ideas around body work (1993).



PAYING FOR ACCESSIBILITY

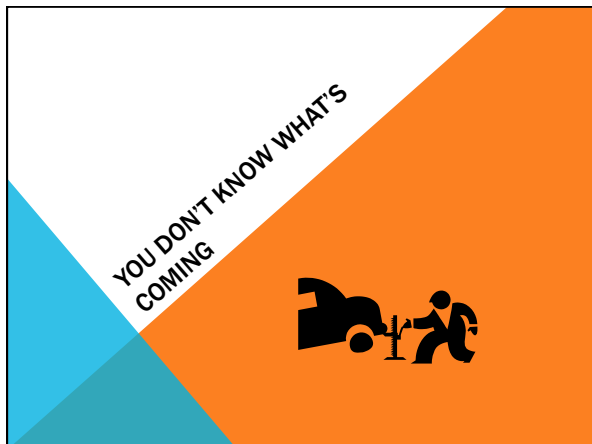
- Additional costs associated with power mobility use included: wheelchair accessible van, home modification, home making, care provision

"We got this new bathroom for 6 thousand dollars."

Maria (54 year old with MS)

PAYING FOR ACCESSIBILITY

- Has the potential to further marginalize some power mobility users and further disadvantage them over their able bodied peers who benefit from the way society (as a field) is set up to accommodate them (Wendell, 1996).
- Allodoxia (Bourdieu 1984)



AGING WITH DISABILITY

"What's happened now is that I ruptured a muscle in my arm [...], It's not painful at all but [...]the whole thing is now [I should...] reduce the number of transfers . [...] I need to get dressed on the floor. [...] All through my life when it comes to having to do something you figure out a way to do it. [...]Getting up on the countertop, I know the OT's just shake their heads because I'm doing stuff that I really shouldn't but I've probably been doing that forever. Like I have to get the dishes up there right? [...] Well now that things are deteriorating a little bit you're going back and you're saying, 'Okay, well I can't do it this way I have to figure out another way to do it so I'm not putting the strain on the muscles .' So it also means that I'll be needing the electric chair right way more than the manual chair."

Jane (62 year old with Spina Bifida)

AGING WITH DISABILITY

- Jane's example, it seems like living in inaccessible places may have contributed to her overuse injury.
- Represents a change in habitus over time, in which participants with more capital and appropriate habitus adapted to better.
- For a few participants the adoption of power mobility was associated with a sense of biographical disruption (Bury, 1982)

AGING WITH DISABILITY

- For many there was more a sense of biographical continuity as participants altered rather than completely revised their life stories (Williams, 2000)



GIVING UP

"Now they tell people don't do that, you know, if you have to, use a power chair [...] or go between a manual and a power chair but take it easy, take care of your body. [When I had my injury @1975] that message was never given. You know, just [...] keep [...] push[ing]. And it becomes ingrained into you and if you give up [...] you feel guilty."

Harold (53 yr old with quadriplegia)

GIVING UP

- Longevity of habits of thought implanted during rehabilitation.
- Discourse of use it or lose it.
- Like the idea of the supercrip (Zola, 1989)



DECONDITIONING

“What I notice now because I went to the power chair from a manual [...] is that I’ve got furniture disease [...] That’s when your chest slides into your drawers.”

Trevor (67 year old with paraplegia)

DECONDITIONING

- The potential for deconditioning was a concern for some participants, given the importance of physical capital
- In terms of appearance, but especially the ability to transfer without assistance.

ASSISTANCE/ACCESS

“And when I travel now I take a helper with me and that’s [...] made a huge difference [...], just from my anxiety level. [...] It’s funny nowadays you’d think it would be more consistent the way hotels and places are set up for access. But I never know what to expect anymore [...], if I get a place with a raised toilet [...] well for me I can’t even use it. So if it’s already a raised toilet then [I would] have to be able to transfer.”

Tom (55 year old with paraplegia)

ASSISTANCE/ACCESS

- Lack of certainty about what accessible would mean might have constrained his ability to travel, if he did not have the means to hire an assistant to go with him.

FLAT TIRES

"Typically you've got to go back to the original shop so you're at their beck and call. [...] You might have found something at four o'clock in the morning. You've got a meeting at eight and you've got a flat tire, [...]
You can't phone BCAA."

Jane (62 year old with Spina Bifida)

FLAT TIRES

- Another example of how society is structured in a way that disadvantages some of those who use powered mobility...

AMBIVALENCE

Occasionally, I would sit and look at the (wheelchair) and I would start crying. And, kicking that effing thing, I don't wanna sit in this thing...[...] I hate this thing...I wanna just get up and walk like I used to. So I had a little bit of mourning like that. And then I'd just be so ecstatic that I could go all over, get a bus pass and go. I could take the sea bus and you know...I could go so many places in my power chair. But, that wore off after maybe...just last year it's been difficult. I've been more aware that I don't think I count...I don't think I'm noticed. I don't think I'm heard. People look at me different. My opinions aren't as important...cause they're up there and I'm down here.

Nadya (52 year old with neurological condition)

AMBIVALENCE

- Winance (2006) suggests that wheelchairs are ambivalent devices for users, because as they open up the possibility of some actions they constrain the possibility of others.

INDEPENDENCE

"The definition of independence in the community for individuals like me has changed [...] No-one is completely independent except some guy living in the mountains, shooting his own game and [...] even he isn't completely independent because he'd be using a firearm that someone else built. So there's no such thing as complete independence. A lot of people think they're really independent, you know, blazing the trail and all that but when they stop to think about it, they're pretty reliant.."

Denis (55 year old, with high spinal cord injury)

INDEPENDENCE

- In this example it is evident that the participant alters the rules of the game, which subordinate those who use the assistance of others to perform activities.

CONCLUSION

WHEELCHAIR USE

- Preliminary findings
- Emphasizes the importance wheelchairs as a form of capital, which must be understood as being used by specific individuals in discrete circumstances.

WHEELCHAIR AWARENESS

- Findings suggest that participants experience times when the devices fade from consciousness, and times when they emerge into consciousness.

WHEELCHAIR AWARENESS

- Although sometimes this awareness of the wheelchair can be associated with “dis-ease” (Winance, 2006; Papadimitriou, 2008).
- Other times this awareness is associated with enjoyment and pleasure (Schilling, 1993)

WHEELCHAIR AWARENESS

- Perhaps what we are seeing is an interplay between power mobility as a form of capital and as a type of habitus.
- The concept of enwheelment is about power mobility as habitus.
- The concepts of wheelchair work and kinesthetic pleasure are about power mobility as capital.
- In the later case the goal is to experience mastery rather than simply getting from place to place without conscious thought.

FUTURE DIRECTIONS

- Work in progress
- See how these themes are maintained over the rest of the study
- Explore differences between provinces and cohorts over time.
- Better understand how the devices emerge into consciousness to facilitate positive experiences.



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