The experience of powered wheelchair users over time. A mixed-methods, longitudinal study

CANWHEEL
improving wheeled mobility of older adults

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REHABILITATION RESEARCH PROGRAM
REINVENTING REHABILITATION PRACTICE: ENABLING ABILITY

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Context

Prevalence of Powered wheelchair

- 65 millions

World Health Organization

- 42,360 power wheelchair users
  - 30% older than 65 years (Smith *et al*. 2016)

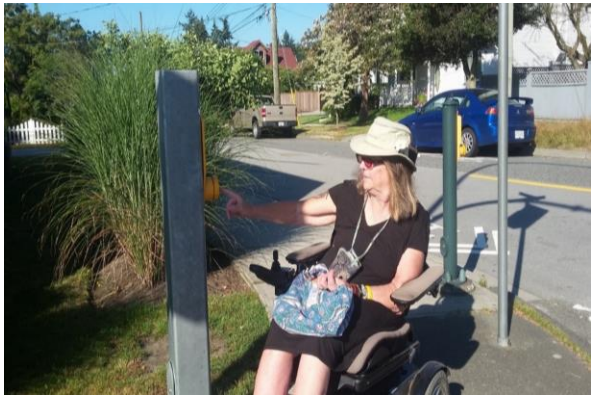
Benefits of Power Mobility

- Increased mobility
- Improve independence
- Enhanced participation in daily activities

Blach Rosen et al. 2012; Edwards and McCluskey 2010; Martins et al, 2016; Stenberg at al, 2014, Pettersson et al 2014

Challenges of Power Mobility

- Usability
- Safety
- Cost
- Accessibility
- Stigma



Blach Rossen *et al*. 2012; Pettersson *et al*. 2015, Salatino et al. 2016; Torkia *et al*. 2015)

Long-term impacts

- 4 months to 1 year
  - Improved ease of activity but not frequency of participation
  - Decreased pain and Discomfort

Life-course perspective

- A person's experience at a certain moment has been influenced and is informed by the context of his or her entire biography
- Prospective and retrospective use
- Help understand the subjective experiences of those ageing with disabilities
- Macro and Micro level

Aim

- To explore the experiences of aging powered wheelchair users over time, using a combined retrospective/prospective life-course perspective.

Methods

Study Design

- Mixed-methods Longitudinal Study : 2 years
  - Qualitative : Baseline, 6 months, 1 year, 2 years
  - Quantitative : Baseline, 1 month, 3 months, 6 months, 1 year, 18 months, 2 years
- Multi-site : Quebec City and Vancouver (Canada)

Inclusion Criteria

- Powered wheelchair user
- Proficient in English or French
- 50+
- Independent powered wheelchair operator
- No cognitive impairments

Data collection: Qualitative

- Individual Interviews
- Evolving semi-structured interview guide
  - First round : wheelchair use and features, participation in activities, mobility challenges, and changes in the wheelchair and user over time.
  - Follow-ups : changes that occurred between interviews and novel topics emerging during the previous interview.

Data collection : Quantitative

- Socio-demographic
- Wheelchair measures
  - Wheelchair Skills Questionnaire for powered wheelchair users (WST-Q)
  - Assistive Technology Outcomes Profile for Mobility (ATOPM)
  - Wheelchair Use Confidence Scale (Wheelcon)
  - Late-Life Disability Index (LLDI)
  - Life-Space Assessment (LSA)
- Hospital Anxiety and Depression Scale (HADS)
- Interpersonal Support Evaluation List-12 (ISEL)

Data analysis

Qualitative

- Transcription
- Prominent themes related to the experience of the users
  - Inductive approach (Thorne, 2006)

Quantitative

- Descriptive statistics
  - Mean, standard deviation, frequency, proportions
  - Examine the variation in time

Results

Participants (n=19)

Characteristics	Value
Age in years, mean (SD)	58,2 (10.2)
Female, n (%)	11 (57.9)
Live alone, n(%)	12(63.2)
Employment status, n (%)	
Retired	9 (47.4)
Unemployed	10 (52.6)
Experience with PWC in years, mean (SD)	8,8 (9.8)
Formal wheelchair skills training, n (%)	5 (26.3)
Funding for PWC, n(%)	
Provincial program	9 (47.4)
Private insurance/self pay	10 (52,6)

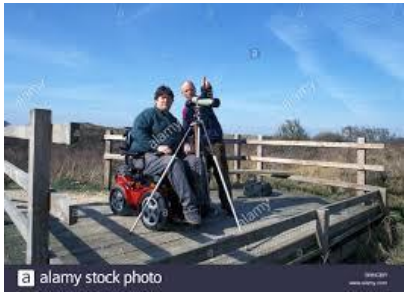
Quantitative

	Baseline		1 month		3 months		6 months		1 year		18 months		2 years	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
WST-Q	88,78	9,32	92,02	9,42	91,46	8,72	90,97	10,16	91,70	9,43	90,58	7,65	91,15	7,49
ATOPM-Activity	47,3	4,03	47,3	4,39	47,2	4,29	46,7	4,86	47,1	4,82	47,0	4,58	47,2	4,27
ATOPM-Participation	55,5	8,13	53,7	7,56	53,7	6,22	54,1	7,53	54,8	7,91	51,6	9,00	55,2	8,38
Wheelcon	86,16	6,21	86,70	8,13	88,45	7,89	86,98	7,17	89,86	8,55	88,26	8,95	86,85	10,09
LLDI-frequency	51,95	8,78	51,42	8,49	52,11	8,92	52,50	7,38	53,40	9,08	50,80	9,21	52,92	7,77
LLDI-Limitation	51,47	6,17	53,44	8,36	52,50	9,12	50,75	8,05	53,75	8,84	54,60	11,83	51,77	10,71
LSA	47,84	15,89	45,26	13,29	44,21	11,06	43,32	11,46	46,06	11,18	43,93	11,30	49,96	13,07
HADS Anxiety	6,84	3,99	7,32	5,07	6,68	4,23	6,53	4,30	6,18	5,16	6,13	4,17	5,92	5,53
HADS Depression	4,21	3,38	5,05	4,56	4,79	3,17	4,59	4,09	3,71	3,92	4,60	3,31	5,00	4,04
ISEL	14,00	3,54	13,37	4,09	13,89	4,37	13,12	4,21	13,59	4,93	13,60	4,91	12,31	4,46

Thematic Analysis

1. It's my legs
2. Wheels of change
3. Getting around

1. It's my leg



- Participants perceived their PWC as a source of freedom and independence, allowing them to participate in their communities
- With time, the PWC became an intrinsic part of the participant's identity.

"PWC is really a part of who you are, almost like an extension of yourself… it comes to symbolize freedom."
Ann, 53, experienced user

2. Wheels of change

- Use changed because of changing physical capabilities
- Driving was perceived as a learning process.
- The participants referred to their past life experiences to explain their skills

" I grew up with horses so I had balance and body awareness, I think it's vital when using a wheelchair because you do need to be aware of the space around you." Denis, 55, experienced user

3. Getting Around

- Housing modifications, transportation, accessibility of public space and climate were important issues related to the built environment
- Great support from family and friends.
- Societal attitudes are still a barrier for participation

3. Getting Around

"I'm 86 years of age and seeing what has happened over these years for people who have handicaps, I mean it's phenomenal what's happening now, being able to get up to curbs, all the different things." Beatrice, new user

Dynamic nature of the PWC use

- PWC use evolves as the person's ability and conditions changed with aging.
- Aging PWC users apply their previous experience in their learning process.
- Despite growing considerations to improve accessibility PWC users still encounter physical barriers.

QUESTIONS ?

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