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

Delphine Labbé, W. Ben Mortenson, Paula W. Rushton, Louise Demers, Bill Miller
Context
Prevalence of Powered wheelchair

- 65 millions

- 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

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

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

Qualitative

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

Quantitative
Participants (n=19)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Value</th>
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<tbody>
<tr>
<td>Age in years, mean (SD)</td>
<td>58.2 (10.2)</td>
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<tr>
<td>Female, n (%)</td>
<td>11 (57.9)</td>
</tr>
<tr>
<td>Live alone, n(%)</td>
<td>12 (63.2)</td>
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<tr>
<td>Employment status, n (%)</td>
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<tr>
<td>Retired</td>
<td>9 (47.4)</td>
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<tr>
<td>Unemployed</td>
<td>10 (52.6)</td>
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<tr>
<td>Experience with PWC in years, mean (SD)</td>
<td>8.8 (9.8)</td>
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<tr>
<td>Formal wheelchair skills training, n (%)</td>
<td>5 (26.3)</td>
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<tr>
<td>Funding for PWC, n(%)</td>
<td></td>
</tr>
<tr>
<td>Provincial program</td>
<td>9 (47.4)</td>
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<tr>
<td>Private insurance/self pay</td>
<td>10 (52.6)</td>
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# Quantitative

<table>
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<tr>
<th></th>
<th>Baseline</th>
<th>1 month</th>
<th>3 months</th>
<th>6 months</th>
<th>1 year</th>
<th>18 months</th>
<th>2 years</th>
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<tbody>
<tr>
<td><strong>Mean</strong></td>
<td>Mean</td>
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<td>Mean</td>
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<tr>
<td><strong>SD</strong></td>
<td>SD</td>
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<td>SD</td>
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<tr>
<td><strong>WST-Q</strong></td>
<td>88.78</td>
<td>9.32</td>
<td>92.02</td>
<td>9.42</td>
<td>91.46</td>
<td>8.72</td>
<td>90.97</td>
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<tr>
<td><strong>ATOPM-Activity</strong></td>
<td>47.3</td>
<td>4.03</td>
<td>47.3</td>
<td>4.39</td>
<td>47.2</td>
<td>4.29</td>
<td>46.7</td>
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<tr>
<td><strong>ATOPM-Participation</strong></td>
<td>55.5</td>
<td>8.13</td>
<td>53.7</td>
<td>7.56</td>
<td>53.7</td>
<td>6.22</td>
<td>54.1</td>
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<tr>
<td><strong>Wheelcon</strong></td>
<td>86.16</td>
<td>6.21</td>
<td>86.70</td>
<td>8.13</td>
<td>88.45</td>
<td>7.89</td>
<td>86.98</td>
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<tr>
<td><strong>LLDI-frequency</strong></td>
<td>51.95</td>
<td>8.78</td>
<td>51.42</td>
<td>8.49</td>
<td>52.11</td>
<td>8.92</td>
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<td><strong>LLDI-Limitation</strong></td>
<td>51.47</td>
<td>6.17</td>
<td>53.44</td>
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<td><strong>LSA</strong></td>
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<td><strong>HADS Anxiety</strong></td>
<td>6.84</td>
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<td>5.07</td>
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<td><strong>HADS Depression</strong></td>
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<td>5.05</td>
<td>4.56</td>
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<td><strong>ISEL</strong></td>
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<td>4.09</td>
<td>13.89</td>
<td>4.37</td>
<td>13.12</td>
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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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