ADULT PERSPECTIVES AND EXPERIENCES OF USING MULTIFUNCTION POWER WHEELCHAIRS IN AOTEAROA, NEW ZEALAND

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Whakaora Ngangahau Aotearoa
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OBJECTIVES OF WORKSHOP

* To share research journey.
* To discuss evidence from the literature to inform occupational practice.
* To present and discuss research findings and implications for practice.
* Discussion of WhOM wheelchair outcome measure to encourage use.
PRESENTATION OVERVIEW

- BACKGROUND
- RESEARCH OBJECTIVE
- LITERATURE REVIEW
- METHODOLOGY
- FINDINGS
- CONCLUSIONS
- WhOM
multifunction power wheelchairs (2 or more functions) can offer users variable compared to static positioning.

- Little research on users’ experiences in the New Zealand context.

- Anecdotal evidence indicates people’s experiences and use of technology is varied. Audit of 100 files, 13 MFPW users, another 6 potential candidates.
RESEARCH OBJECTIVE

- To enable users’ voices to be heard by providing detailed description of their day to day experiences and perspectives of multifunction power wheelchairs.
LITERATURE REVIEW

- The **voice of the user** in the social model of disability and research.

- The **benefits of power wheelchairs** on users’ lives such as increased mobility, reduced pain.

- **Environmental factors** affecting mobility.

- The **use of power functions**.

- The role of therapists in **wheelchair assessment and provision**.

- However there were few researchers discussing users’ personal experiences and perspectives.
The voice of the user

- **Increased client centred approach needed** (Hedburg, …, 2000; Rippat & Booth, 2005; Weiss, … 1999).

- **Environment and transport issues need to be addressed** (Belcher & Frank, 2004; Brandt, …, 2004; Chaves, …, 2004; Evans, …, 2007; Edwards & McCluskey, 2010; May & Rugg, 2010; Reid, …, 2003).

- **Many positive and effective benefits of power wheelchair functions reported** (Davies, …, 2003; Dewey, …, 2004; Ward, …, 2010).
Benefits of power mobility

- Increased mobility (Davies, …2003).
- Increased participation (Miles-Tapping & Macdonald, 1994; Petterson, …2006; Rousseau-Harrison, …2009).
- Greater autonomy and self sufficiency (Bunning, …2001).
- Reduced need for transfers and assisted pushing (Frank, …2000).
- Increased freedom and reduced physical burden on carer for attendant pushing (Frank, …2010).
- Increased independence and quality of life (Davies, …, 2003; Edwards & McClusky, 2010; Koczur, …2000).
- Improved physical, psychosocial functioning (Amos, …2001; Pitts, 1995; Rappl & Jones, 2000; Stewart, 1991).
Considerations for powered mobility device

- **Usability**: satisfaction with which individual user can achieve specified goals in particular environment (Samuelsson, …, 2001).

The following considerations are from a consumer panel (Batavia & Hammer, 1990):

- **Learnability & operability**: ease of learning and ability to use it within a reasonable period of time, including setup and training required (cognitive load).
- **Repairability**: extent to which repairers can repair the device in a reasonable amount of time, ready availability of parts, whether suppliers must conduct repairs.

- **Effectiveness**: extent to which the living situation is improved, including enhancing function and/or independence as perceived by the consumer
  - ...embodiment (Winance, 2006)
These two factors also identified by Brienza, ….1995

- **Dependability**: extent to which a device operates with repeatable/predictable levels of accuracy under all conditions of reasonable use.

- **Durability**: extent to which a device will continue to operate for an extended period of time.
Researchers identified many **physical** environmental barriers such as:

- narrow door widths, restricted and poorly designed living spaces, uneven terrain, poor community access and transportation (Evans,…2007; Mortenson,…, 2005; Reid,…, 2003).

And **cultural, socioeconomic, institutional and social** environmental factors such as:

- users feeling they were treated differently (McMillen & Soderburg, 2002).
Types and benefits of power functions

**Tilt in space:** to assist with transfers, increase stability; weight shift; comfort; facilitate rest
(Assaoui,…2001; Lacoste & Dansereau, 2001; Engstrom, 2002; Ward, 1994).

**Seat high low:** to elevate to assist with reach; facilitate transfers; adjust height for communication
**Recline:** to increase stability, rest and comfort (Greene & Roberts, 2005; Lange, 2001; Pfaff, 1993). Prevent collapse or fall forward such as low muscle tone (Engstrom, 2002). Accommodate limited hip flexion, fixed kyphosis. Meet the need for frequent back angle changes, reduce transfers in and out for rest, manage fatigue & pain, manage medical needs, pressure relief (Pfaff, 1993).

**Elevating leg rests:** manage oedema; reduce pressure (Diciano, …2009).
Standing: enables hands free standing, pressure relief, social interaction, extends reach (Arva,…2009; Meyer, 2010), change of position, reduce spasm and contractures (Gear,…1999), double metabolic rate, increase respiration and circulation (Ainsworth,…2000), increase activity (Shields & Dudley-Javoroski, 2005).

Combined functions: Tilt and recline provide the most pressure relief when use in combination (Aissaoui,…2001; Vaisbuch,….2000). Use of various functions has been found to be frequent, individual and complex (Sonenblum,…2008; Ward,…2010).
Assessment and provision

- Occupational therapists are involved in wheelchair and seating because firstly mobility and/or positioning present a challenge to occupational engagement.

- Secondly wheelchair and seating are part of a solution that can enable occupation.

METHODOLOGY

Qualitative descriptive methodology (Ontology: relativism; epistemology: social constructionism) provided the focus for: understanding the participants’ perspectives and the meaning and context in which they used their chairs.
Participants: A convenience sample of 10 adults (over 16 years old, long term physical disability, used wheelchair for longer than 6 months).

Data Collection: individual semi structured interviews

(Northern X Regional Ethics Committee Approval)
### Participants

Participants included 5 males, 5 females:

<table>
<thead>
<tr>
<th>Medical diagnosis</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amputee</td>
<td>2</td>
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<tr>
<td>Neuromuscular</td>
<td>4</td>
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<tr>
<td>Multiple sclerosis</td>
<td>1</td>
</tr>
<tr>
<td>Polio, stroke</td>
<td>1</td>
</tr>
<tr>
<td>Spinal cord injury, tetraplegia</td>
<td>3</td>
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# Background of Participants

<table>
<thead>
<tr>
<th>Background</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>5</td>
</tr>
<tr>
<td>In relationship</td>
<td>5</td>
</tr>
<tr>
<td>Parent of dependent children</td>
<td>2</td>
</tr>
<tr>
<td>Part time worker</td>
<td>3</td>
</tr>
<tr>
<td>Full time worker</td>
<td>2</td>
</tr>
<tr>
<td>Retired</td>
<td>4</td>
</tr>
<tr>
<td>Student</td>
<td>1</td>
</tr>
</tbody>
</table>
## Power Wheelchair Functions Used

<table>
<thead>
<tr>
<th>Participants</th>
<th>tilt</th>
<th>recline</th>
<th>seat high low</th>
<th>4X4</th>
</tr>
</thead>
</table>
| 1            | tilt | recline | seat high low | 4X4 | rear wheel drive  
| 2,3          | tilt |         | seat high low |     | mid wheel drive   
| 4,6          | tilt | recline | seat high low |     | mid wheel drive   
| 5            | tilt | recline |               | elevating leg rests | mid wheel drive   
| 7            |      | recline |               | standing | rear wheel drive  
| 8,10         | tilt | recline | seat high low | elevating leg rests | mid wheel drive   
| 9            | tilt | recline |               | elevating leg rests | mid wheel drive   |
FINDINGS

• Thematic analysis found repeated, meaningful patterns descriptive of users’ perspectives and experiences…
Importance of Mobility

- Improved mobility

- *I don’t miss walking at all because at the end of it I was just trying to put one foot in front of the other and not fall over, I am more independent now than I have been in the last 10 years*

- Barriers to mobility: unreliability, breakdowns, repairs, weight, …
Environmental Factors

- The biggest issue is making sure that everywhere I go is accessible.

- I have been stuck three times in a lift with this wheelchair, twice at our local school. I am not sure if it is a water powered lift but it is a lift that has a 300 kilogram weight limit, one of those smaller lifts, and see me and the wheelchair weigh 278 kg, and I know there is meant to be a safety margin built into those lifts ...
It is very difficult to get reliable taxi and they have school rounds and if you have doctors appointment at 9am, spouse has to help, expensive to use mobility taxis, limited subsidies and not reliable so prefer home vehicle.

I have some funding money for driving modifications, self drive but they are so expensive, astronomical in terms of price and I only have limited funding and that won’t pay for them, it will barely put a hoist into a van let alone all the other stuff that needs doing, so I haven’t done anything about that, I don’t know what to do!
Benefits of Power Functions

- With the high low function in particular I can cook and I can reach things...

- Interacting with people is huge, I am a really social person so even around here if I have people over and we are sitting around the kitchen bench I will raise my chair up a little bit so I am sitting at the same level...
Combined Functions

...I use them [functions] all at the same time, the tilt, recline and elevating leg rests. At the moment I have got the seat tilted, that stops me from sliding forward, and then I put the back... back and that allows me to have my head back without having it down all the time, if I was to have the seat flat I would be sliding forward...
...the recliner is one I use a lot, I use that every day, a couple of times a day, if my back is uncomfortable I recline and have a bit of a stretch.

The chair takes a lot of the pain away from me... the pain is reduced from 10/10 to about 4/10. I don’t seem to spasm too badly in the chair. I spasm more when I am lying in bed.
Importance of Independence

- Independence was important to all participants, individually determined and not linked to level of impairment...

You can’t put a price on independence. Independence is huge!
Barriers to Independence

- ... people might not realize the whole mental and emotional wellbeing becomes impaired as well because you are having to face things [equipment failure] that you shouldn’t have to face all the time...

- ... [wheelchair breakdown], to me it was almost like my disability turning around and saying “you think you are in control, but you’re actually not” and that’s it, this is where I am at and I don’t like it and there is absolutely nothing I can do about it ...
- **Cost, funding**... *I had to justify why I needed high low and it is just like I wouldn’t ask for it if I didn’t need it...*

- **Wheelchair knowledge** ... *at the time I didn’t have a clue what was out there, if I had known then and I was given choices I would have got this chair...*

- **Skills, time, attitudes, actions, transitions, complexity**... *I think the therapist that was dealing with me got sick of me not fitting into the mould...*
**Weight:** One of the important things for me is if the chair breaks down other people have to push it and it is really heavy, if you have 105 kg in a chair alone and then you add the person it makes it a pretty heavy chair, or a pretty heavy load to push.

**Trialling/time:** I trialled three chairs, I put them through their paces because I didn’t want to get the wrong one...
Social Independence

- You are just down here and they are all talking away up there and you can’t hear what they say whereas if I had that lifting chair I could have participated in a lot of those things over the years but the powers that be wouldn’t justify that.

- High low important because stroke makes it very hard to make conversation…
I think people suddenly see you in a different light as well when you suddenly stand up and when they see you do that in a bar it gives them something to talk about and it is quite a good experience … people tend to ignore people in wheelchairs when you are out in public…

…the power chair is an extension of my body.

People stare at the power chair, it is the whole curiosity thing and they wonder if there is something wrong with you mentally when it is just a physical thing
IMPROVED MOBILITY

...the basis for getting to where the living is...
ENVIRONMENT

... a facilitator or inhibitor to mobility and engagement...
* ... enabled engagement in an inclusive accessible environment...
INDEPENDENCE IN OCCUPATION

* ... made possible by the improved mobility and functionality within the inclusive environment...

“WELL-DOING”

(Engagement in meaningful, positive occupation (Whitcombe-Shingler, 2013)
PERSONAL AND SOCIAL IDENTITY

...important...
this culminated in...

“WELL-LIVING”

Defined as self-determined, satisfactory living.
(Whitcombe-Shingler, 2013)
Well-living

“Well-living” can be achieved when mobility, function and environmental factors are addressed effectively.

It is proposed that “well-living” provides a useful concept that reflects what the participants were describing and “well-doing”.

“Well-living” is defined as self-determined, satisfactory living (Whitcombe-Shingler, 2013).
The literature and findings show that individuals with significant physical impairments can benefit greatly from multifunction power wheelchair use.

The criterion for the provision of multifunction power wheelchairs needs to be broad, because of the benefits and potential they offer individuals: I am very lucky with the OT I had, they jumped through hoops to enable me to get this chair ... what if other people don’t have such a great OT who knows how to push for these things you know, um, do they miss out?

Conclusions:
A person centred approach to outcome measures is vital, as there is a user demand for enhanced client centred practice, challenging practice norms.

Closer independent appraisal of new equipment to improve affordability, reliability and design is needed.

Inclusion of user groups in services is necessary to ensure users have on-going voice to highlight the main issues and enhance their rights.
Occidental challenges need to be addressed as they appear beyond the time of initial provision.

Further inclusive research (Layton, 2012) is needed about multifunction power wheelchair intervention and outcomes that include: usage, training, reducing architectural barriers, and accessing transportation.

This study goes some way to capturing the voice of users of power wheelchairs whose lives may be either enhanced and or limited by the type of mobility solution they end up being provided ... 

The amount of independence and freedom I’ve felt from having this chair I’d want others to have as well, also experience that ...
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Thank you for your interest
Questions welcome

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