Adult perspectives and experiences of using multifunction power wheelchairs in Aotearoa, New Zealand.

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ABSTRACT

This study explored the perspectives and experiences of adults using multifunction power wheelchairs; thereby capturing their 'voice'. A multifunction power chair in the context of this research is defined as a power wheelchair which has two or more of the following power functions: tilt in space; seat elevate; recline; stand and power elevating leg rests.

A qualitative descriptive methodology using in-depth, individual semi structured interviews was conducted with a convenience sample of ten wheelchair users from New Zealand. The main themes identified were: mobility, environmental factors, independence, personal and social identity and 'well-living'.

The findings gave rich detailed descriptions of some of the benefits and challenges for a group of multifunction power wheelchair users. The benefits identified included increased mobility and independence. Improved personal identity and communication through the use of an elevated seat or standing position which achieved inclusion and face to face communication. Greater social participation and occupation, 'well-doing' achieved a state of 'well -living'.

Challenges related to environmental access, repairability and the increased weight of the wheelchairs which resulted in transportation problems. Whilst the wheelchairs enabled increased autonomy and independence, this in turn led to a series of different issues, such as person centredness, practice knowledge, funding criteria, and backup support which should be considered during the process from wheelchair assessment to provision and beyond. Further research exploring the experiences of wheelchair users is required.

Keywords: multifunction power wheelchairs, independence, well-living, personal identity, communication, environmental factors

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Focussing the study

All of us use wheels for mobility of some sort whether it is a pram, bicycle, scooter, car, bus or train. Wheels have been used through history with the oldest representation of a wheeled chair coming from China, dated about 525 A.D. (Kamenetz, 1969). With the exception of when we are very young, the use of wheels is part of our secondary means of mobility; otherwise we are primarily using our own bodies to move. Most people exist on a mobility continuum which changes throughout our lives; starting as babies when we develop the ability to control posture and movement. However a person's personal mobility can abruptly change with acquired impairments such as a stroke or spinal cord injury (Frank, 2000; Hockenberry, 1995), or gradually change due to a deteriorating physical condition (Williams, 2007). For others independent mobility may be a lifelong challenge due a congenital impairment. Impairment has always been a natural part of human life. For example census figures report that one in five New Zealanders experience disability (Ministry of Health, 2004; Office for Disability Issues, Ministry of Social Development, 2006). Globally there is an increase in chronic health conditions and an ageing population (World Health Organisation, 2011). Older adults are a large group of wheelchair users (Clarke & Colantonio, 2005).

For many people where independent mobility changes, wheels are often incorporated into their personal mobility devices, either to help walk with a frame, or to replace walking with a wheelchair. People with impaired mobility often use manual wheelchairs or for a significant number of people who cannot manage to self-propel a wheelchair then power wheelchairs are used. It is estimated there are 1 to 2 % of the populations of developed countries such as the USA using wheelchairs (Brault, 2012) and the need (though not the provision) is much higher in developing countries with the ravages of poverty, disease and war (Winter et al., 2012).

Advancements in technology, as well as social-political forces (Woods & Watson, 2003) have led to the development and use of wheelchairs which are capable of more functions than standard power wheelchairs. These are multifunctional powered wheelchairs with additional power functions such as seat tilt in space; seat high low (elevate); back recline; stand and elevating leg

rests. These functions purport to enable people with higher levels of impairment to achieve greater participation in day to day life. The International Classification of Functioning, Disability and Health (ICF) definition of participation is "involvement in life situation" (World Health Organisation, 2001) and this broad definition will be used in this thesis.

At the time of writing, multifunction power wheelchairs were a relatively recent wheelchair option for many adult users in Aotearoa, New Zealand, therefore users' perspectives are essential to understanding the effects of this technology on people's lives. As a background to the study a retrospective review of the closed files of 100 people (who were clients of a complex wheelchair and seating service, discharged over a four month period) was completed: there were 13 people who were using multifunction power wheelchairs and possibly another six people whose reported problems indicated they may have possibly benefited from additional power functions (refer Appendix 1) for example a power reclining back to manage pain. Therefore this study aims to explore some of the personal perspectives and experiences shared by adults who are currently using multifunction power wheelchairs to gain further information.

Reasons for this study

Whilst wheelchairs are important to enable people to move from place to place, wheelchairs can also be an integral component for the positioning of a person to carryout activities (Chaves et al., 2004). The technology of multifunction power wheelchairs is being increasingly recommended and prescribed by health professionals, such as occupational therapists, because it offers users variable positioning as well as improved mobility. Provision is often related to specific funder related outcomes to achieve the following: getting around inside the home safely, managing living alone, study or training, working or being a caregiver of a dependent (Ministry of Health, 2008, 2010), or for broader social rehabilitation outcomes for people whose impairments result from an accident (Accident Compensation Corporation, 2001).

Many of the studies available about wheelchairs and seating tended to focus on the mechanics and quantifiable measures of the wheelchair and seating and far less on the users' perspectives. Subsequently I became increasingly interested in clients' personal experiences of multifunction power wheelchairs. The users of these wheelchairs tend to be people who are most reliant on a

power wheelchair for any independent mobility and movement. Those with multifunction power wheelchairs tend to spend a considerable amount of time using the wheelchair, and therefore, by necessity it has to be integrated or accommodated in most aspects of their lives, both by themselves, their families and carers. Observations and anecdotal evidence from clients indicates a range of life experiences and outcomes. However, as yet little is known from the literature available about the holistic effects that being prescribed a multifunction power wheelchair has on the recipient. The voice of the user needs to be the central focus of research to optimise outcomes and ensure future needs are met. Many positive changes have been initiated through the collective voice of disabled people such as challenging discrimination, contributing to the development of the social (constructionist) model of disability (Shakespeare, 1994) and more inclusive wheelchair and environmental design (Keates & Clarkson, 2004). The journey to a more fair and equal world is aspired to in legislation such as the New Zealand Disability Strategy (2001) which explains disability like this:

> Disability is the process which happens when one group of people creates barriers by designing a world only for their way of living, taking no account of the impairments other people have. Our society is built in a way that assumes that we can all move quickly from one side of the road to the other, that we can all see signs, read directions, hear announcements, reach buttons, have the strength to open heavy doors and have stable moods and perceptions (p.9).

Technology assists with engagement in everyday occupations. However matching people and technology can be a complex process because people's expectations of, and reactions to, technology are individual and varied. Therefore this research aims to provide rich, detailed descriptions of adults' perspectives and experiences of using multifunction power chairs which enables the user's voice to be heard.

Context of the study

The genesis for this research was developed from my work experience as an occupational therapist (Maori translation: kai whakaora ngangahau) in a complex wheelchair and seating assessment service. An interest in working with people with physical disabilities developed from my undergraduate studies in the early 1980s. Wheelchair provision has been a large part of

occupational therapy practice in assisting people to achieve or maintain independence and engagement in meaningful occupations of daily living. This involves actively acknowledging the person's goals, priorities, occupations, experiences and working in a collaborative respectful manner. This is "person-centeredness" (Wright-St Clair & Seedhouse, 2005) which acknowledges the person's right to autonomy and self-determination. Occupational therapy is a profession which recognises the interaction between the person, their occupations and their environment. Occupation in this context can be seen as the ability to choose, organise and engage in meaningful tasks and community participation (Townsend & Polatajko, 2007). One method of addressing environmental barriers to occupation is through enhancing personal mobility (Mollenkopf et al., 1997). This is because without personal mobility a person cannot always move and position themselves to effectively engage in activities and tasks of their choosing.

Through experience, I have developed a greater understanding of clients' expertise and perspectives of what is required as they self-determine their individual lifestyles; clients have been my greatest teachers. Developments in technology have given people many more choices and options (although this can be tempered by available funding), and I am keen to further understand users' experiences and insights. With a work background in the area of wheelchairs and seating for over twenty five years, it has been fascinating and heartening to see the possibilities open up for clients through technology that can enable increased occupational engagement.

Overview of the study

This introduction has outlined the focus and background of this study. A description of the content of the thesis is now presented. A review of the literature relevant to the research question is outlined in chapter two. Chapter three describes the qualitative descriptive approach used in this study and why this is appropriate. The details of how the study was conducted, recruitment of participants, ethical considerations, the process of analysing the data, and what strategies were used to ensure trustworthiness are then presented. Chapter four presents the findings and reports the identified themes resulting from the analysis. Chapter five is the discussion of the findings, the implications for users and other stakeholders and recommendations for future research. Chapter six, the final chapter, is the conclusion presenting a summary of the key findings. The second chapter will now focus on the findings from the literature review.

Chapter 2: Literature Review

Introduction

Literature relating to wheelchairs was reviewed to inform the focus of this study exploring adults' experiences and perspectives of using multifunction power wheelchairs. In developing this literature review a search was conducted using a number of electronic databases including CINAHL, Ovid Medline, Scopus, Compendex and Google Scholar. The time span considered was 1990 to 2012. Search terms included: wheelchairs, multifunction, power/electric, quality of life, occupational performance; activities of daily living, elevate/high low seat function, elevating leg rests, tilt in space, sit to stand/standing and recline. Iterative strategies were used because no specific key words were available throughout the period covered, for example there is no set key word for multifunction power wheelchair.

Further literature was obtained from a review of the references used in each of the articles obtained through the database searches. Guidelines for critical review were used to appraise the literature (Letts et al., 2007). The literature fell into the following broad categories: the voice of users; the impact powered wheelchair mobility in general has had on the lives of users; the use of various individual and combined functions on a power wheelchair; and wheelchair assessment and provision. As each of the main categories had a relevance to powered mobility it was considered important to discuss the implications.

There were a limited number of published articles documenting peoples' experiences of using multifunction power wheelchairs. Unfortunately there were no articles located specific to the New Zealand context to compare this research to. Multifunction power chairs appear to be a relatively new wheelchair option for many users and therefore little research has been completed in this area. It is not known at this stage what percentage of New Zealand wheelchair users have multifunction power wheelchairs however there is anecdotal evidence that multifunctional chairs are being increasingly used (Refer Appendix 1). A report about services in the United Kingdom

highlighted that there is a greater need for more complex wheelchair solutions because of the emphasis on promoting independence in community living (Flemming, 2003). This thesis addresses a gap in the literature by exploring the use of complex multifunction power wheelchair use in New Zealand. There were six main categories in the literature that I considered relevant to this study. The first of these and the most important is the voice of the user; secondly, the benefits of power wheelchair mobility; thirdly, the considerations for power wheelchair mobility; fourthly, the environmental factors affecting power wheelchair mobility; fifthly, the types and benefits of power functions; and lastly the sixth theme, was wheelchair and seating assessment and provision.

The "voice" of the user

Paul Tobin (2012), American Spinal Association President, who uses a wheelchair himself and is active in seeking recognition of the need for complex wheelchair and seating solutions, highlighted key issues in the following statement:

> Without proper mobility equipment, many individuals cannot live with dignity and independence. They may be confined to their homes or forced into nursing homes. They might not be able to get involved in their communities, discover recreational or educational opportunities, attend family or religious gatherings or seek employment. They lose their voice and, ultimately their empowerment.

Basic power wheelchairs do not always address the needs of wheelchair users. This is because a static sitting position does not enable a person to move effectively and adjust for function. Unaddressed problems of restricted and limited mobility, leads to isolation from society and disempowerment.

The development and growth of the social model of disability movement since the 1970s (Oliver, 1990; Shakespeare, 1994) includes the voices of wheelchair users. The voices are growing in number and need to be heard. Initially it was only the stereotypical healthy active wheelchair users such as people with paraplegia with full upper body function who were visible in society. People who were very dependent were not able to leave their homes and even now have lower incomes and are underrepresented in the workforce (Statistics New Zealand, 2002). However in the last one to two decades technology and inclusive design (Keates & Clarkson, 2004) has enabled more people with higher levels of impairment to actively engage at all levels of society

and thus express their voices. This is reflected in socio political changes such as human rights legislation (New Zealand Government, 1993) and literature and research which have increasingly included the voice of the users (refer Appendix 2). The key messages are that an increased client centred approach is needed (Hedberg-Kristensson, Ivanhoff & Iwarsson, 2000; Ripat & Booth, 2005; Weiss-Lambrou, Tremblay, Le Blanc, Lacoste & Dansereau, 1999), environment and/or transport issues need to be addressed (Belcher & Frank, 2004; Brandt, Iwarsson & Stahle, 2004; Chaves et al, 2004; Evans, Frank, Neophytou & De Souza, 2007; Edwards & McCluskey, 2010; May & Rugg, 2010; Reid, Angus, McKeever & Miller, 2003) and there are many positive and effective benefits of power wheelchair functions reported by individual users (Davies, De Souza & Frank, 2003; Dewey, Rice-Oxley & Dean, 2004; Ward et al., 2010). Therapists need to take note of the many benefits documented above. The other categories identified in the literature will now be discussed. These are: benefits of powered wheelchair mobility; considerations for powered wheelchair mobility; environmental factors affecting mobility; benefits of power functions; wheelchair assessment and provision.

Benefits of power wheelchair mobility

Another important category found in the literature relates to benefits of power wheelchair mobility. Studies of powered mobility equipment have investigated the impact on a person's general ability to participate in their life and wider community. Many benefits of powered mobility have been documented in the literature that extends further than people just being able to move from one point to another (Batavia, Batavia & Friedman, 2001; Minkel, 2000; Stumbo, Martin, & Hendrick, 2009, Taylor, 1993; Ward et al., 2010). Auger et al.'s (2008) systematic review of the outcomes of powered mobility devices for middle-aged and older adults found statistically significant findings related to many positive outcomes such as: increased participation, improved psychological functioning and increased comfort. Therefore powered mobility devices should be presumed to be potentially helpful. According to Auger et al. (2008) more studies are needed that use prospective designs as these better define user groups and give clear conceptual frameworks for measuring interventions and outcomes. However more time and resourcing are required for research of this type and therefore it is no surprise to find no published prospective studies in a small country like Aotearoa, New Zealand.

The benefits of powered mobility were evident in studies from many countries across a range of health conditions. The quantitative American study by Buning, Angelo and Schmeler (2001) of

pre- and post- scores for participants transitioning to powered mobility showed greater autonomy and self-sufficiency in daily tasks. Petterson, Tornquist and Ahlstrom (2006) found a quantifiably large positive effect of power wheelchair usage on activity and participation for 37 Swedish people following a stroke for example increased outdoor leisure. Similarly, Edwards and McClusky's (2010) surveyed over two hundred Australian power wheelchair and scooter users who reported increased independence and quality of life. British studies also identified many benefits such as increased independence, reduced need for transfers and assisted pushing (Frank, et al., 2000); increased freedom and reduced physical burden on family/ friends/carers for attendant pushing (Frank et al., 2010); perceived reduction in pain and discomfort, and improved levels of mobility and quality of life (Davies, De Souza & Frank, 2003). One Canadian study did ask power wheelchair users how they felt about their power wheelchairs, and they reported the power wheelchair enabled them to participate more in life (Miles-Tapping & Macdonald, 1994).

Rousseau-Harrison et al.'s quantitative research on the impact of power wheelchair acquisition also shows a positive increase in social participation (2009). Koczur, Strine and Peischa (2000) used case studies to show that wheelchair technology can assist people with disabilities to live life more independently. Improved wheelchair positioning has been found to also improve functional ability as demonstrated by improved respiration and greater upper limb movement (Amos et al, 2001). Articles also provided expert clinical opinion supporting the need for improved positioning for swallowing, breathing, interacting and to reduce the risk of deformity (Pitts, 1995; Rappl & Jones, 2000; Stewart, 1991). In summary these studies were about standard power wheelchair use which enabled people to have improved mobility and a more supportive, stable seat base. Therefore what value added benefits could be expected for multifunction power features?

Considerations for power wheelchair mobility

The third category relates to factors to be considered in relation to power wheelchair mobility, for example the such as ease of use can be an essential factor in the decision for wheelchair selection.

Samuelsson, Larsson, Thyburg and Gerdle (2001) showed in their study of client centred wheelchair intervention that 'usability' varies from one user to the other. It relates to the "satisfaction" with which an individual "user can achieve specified goals in a particular

environment" (p.682). 'Learnability' and 'operability' are also important considerations suggested by Batavia and Hammer's (1990) consumer panel; 'learnability' being defined as "the extent to which the consumer, upon initially receiving the device, can easily learn to use it and can start using it within a reasonable period of time, including whether specialised training is required" (p.431). Other considerations include: the time required for the consumer to learn to use the device effectively, the clarity of the equipment operational instructions, and the extent of setup and training required (Batavia & Hammer, 1990). The lack of provision of written instructions such as a user information booklet with wheelchairs is also highlighted as an issue (Jelier &Turner-Smith, 1997). In addition, 'cognitive load', that is the degree of learning required, needs to be considered (Scherer, 1996). For instance, in the 21st century of technological explosion/advancement, many people would be familiar with the frustrating experience of trying to learn to operate a new electronic device such as a mobile phone. This is similar to learning to use new electronic power wheelchair controls and the principles of inclusive design need to be taken into consideration in wheelchair operability and learnability.

The problems and benefits as perceived by users is also revealed in the UK study by Frank, Ward, Orwell, McCullagh and Belcher (2000) where 113 subjects were followed up following provision of new power wheelchairs. The results showed 15 mishaps, such as tipping from wheelchairs and 39% component failure such as control box failure. However new activities were undertaken by 50% of users and 85% of users felt the power wheelchairs made life easier for carers by increasing independence, reducing transfers and the need for pushing. Frank et al.'s (2000) study also indicates the important need for follow-up of users by wheelchair services. Research that follows up users' experiences will provide useful feedback and allow informed wheelchair choice.

'Repairability' is also an important criterion (Batavia & Hammer, 1990, p.432), defined as "the extent to which repairers could repair the device within a reasonable amount of time, the ready availability of replacement parts, and whether suppliers must conduct repairs." Other factors include: what is the turnaround for the most common problems; are there fault diagnostic routines; and is there easy access to suppliers? In addition, "dependability' and 'durability' are two further criteria identified by Batavia and Hammer (1990). 'Dependability' is defined as "the extent to which the device operates with repeatable/predictable levels of accuracy under all conditions of reasonable use" (p.431). 'Durability' is defined as "the extent to which the device

will continue to be operable for an extended period of time" (p.431). These two factors were also identified as a priority by a focus group of consumers and professionals (Brienza, Angelo & Henry, 1995). The current power wheelchair range is 10 to 25 kilometres dependent on the battery size used. The overall durability or life expectancy of multifunction power wheelchairs used is approximately 5 years (personal communications from repair technicians and suppliers). Thus, as the fleet of current power wheelchairs age, replacement and updating of this technology must be an important factor for on-going consideration for all stakeholders in New Zealand and other countries. This leads to the question: what are the experiences of people using the current multifunction power wheelchairs? This answer will assist with identifying whether the criteria of 'usability', 'learnability', 'operability', 'durability', 'dependability' and 'repairability' are being met. Another consideration for power wheelchair mobility use is environmental factors.

Environmental factors affecting power wheelchair mobility

Environment for the purpose of this research is defined by Law et al. (1996) as the context within which occupational performance takes place and it is categorized into cultural, socioeconomic, institutional, physical and social. Researchers found there can be issues with environmental barriers such as small door frames and uneven terrain and the practical use of power wheelchairs for example as people age (Evans, Frank, Neophtou & Desouza, 2007; Mortenson et al., 2005). Also poor community access and transportation was an issue highlighted in a study of women users (Reid, Angus, McKeever & Miller, 2003). The effectiveness of the equipment in improving life was identified as a priority by users (Batavia & Hammer, 1990) and other stakeholders. At a 2007 American conference, stakeholders identified key priority mobility topics that included: the impact of long term wheelchair use, the environmental influences on mobility, wheeled mobility versus assisted walking, relating activity and participation to outcomes, the impact of wheelchair evaluations, translating research into design, and the impact of design on function (Sprigle, Cohen & Davis, 2007).

The few articles describing people's personal experiences of using a power wheelchair in any depth included the following qualitative studies (which all highlighted environmental issues among other issues): Reid et al. (2003) explored the experiences of eleven women wheelchair users, 6 of whom used a power wheelchair. The rich findings highlighted the impact of restricted and poorly designed personal and public living spaces on autonomy, and the improved mobility

and quality of life with a power wheelchair. It highlighted the need for further research on the impact of the environment and the meanings users place on their wheelchairs. The study did not describe the type of power wheelchairs in any depth which leads one to assume they possibly had few power functions. Barker, Reid and Cott's research (2004) of the experiences of 10 wheelchair users post stroke (of which 2 users had power wheelchairs), considered the acceptance and meanings of wheelchair use. Overall increased mobility was an identified benefit especially with a power wheelchair and further research was recommended to explore the challenges and benefits. Fifteen peoples' experiences of dependence on assistive devices were explored by McMillen and Soderberg (2002), of which 8 people used power wheelchairs. Participants reported achieving a more normal life, but having issues around acceptance, feeling they were still treated differently and inaccessibility issues. These in-depth interviews with users showed that accessible, inclusive environments and the value and meaning people construct around their power wheelchair use are more important to them than quantifiable measures. This provides support for the use of qualitative descriptive methodology to explore users' perspectives of multifunction power wheelchairs within their environment.

Types and benefits of power functions

There is a greater need for more complex wheelchair solutions because of the increased emphasis on promoting independence in community living (Flemming, 2003) therefore the benefits of powered mobility need to be explored in more depth (Barker et al., 2004). There is an expanding need for adaptive strategies to offer maximum independence in environments. 'Flexibility' was a similar criteria identified by a panel of consumers (Batavia & Hammer, 1990), they defined it as "the extent to which the device is provided with available options from which the consumer may choose (p.431)." Additional factors the panel also suggested for consideration were: what options are available? And are these options important to the consumer? These options can include multifunction power wheelchairs.

Power functions give power wheelchairs additional options and capabilities. The literature identified the benefits of specific single and multiple wheelchair functions. Power wheelchairs are becoming increasingly complex, and a study of the effect of visual perception, visual function, cognition and personality on power wheelchair use in adults indicated that good visual

function, visual perceptual skills and various aspects of cognition are necessary for effective power wheelchair use (Massengale et al., 2005). In addition, currently a separate control used by an attendant such as a carer or family member is often provided to assist users who struggle to drive a power wheelchair fulltime. Technology is continuing to develop and there are new wheelchair functions such as stair climbing, intelligent collision avoidance and navigation assistance (Simpson, 2005; Viswanathan, Boger, Hoey, Elinas, & Mihailidis, 2007) to assist with independence and safety. These functions were not available to users in New Zealand at the time of writing. However at some point, as with all new developments, users will expect consideration of these functions as potential options, therefore evaluation and user feedback will be required. There is currently a range of power wheelchair bases available with different drive wheel settings which can include any of the five power functions listed in the following Table one.

Table 1: Power wheelchair function options

Functions Drive wheel	Tilt in space	Seat elevate	Back recline	Elevating leg rests	Standing
Rear wheel	*	*	*	*	*
Mid wheel	*	*	*	*	*
Front wheel	*	*	*	*	*
4 wheel drive	*	*	*	*	

Notes: Power wheelchairs are available with one or more of these functions*, although the movement range of the function may vary.

The battery size can vary and the motors can range from 2 or 4 pole to gearless brushless motors. Wheelchair suspension, tracking setups and performance can vary and useful independent end user feedback is available online (United Spinal's Techguide, 2012). Power wheelchairs have become more complicated in order to meet more complex needs. Progressive neuromuscular disorders can result in weakness, limb contractures, spinal deformities, breathing and swallowing problems that need to be prospectively considered when providing wheelchair and seating. A discussion of the literature around each of the five power wheelchair functions now follows as it gives an important background to the types of equipment the participants in this research used.

Power tilt in space function

Tilt refers to the angle of the seat surface, where the angle of the back and seat remain constant and the entire system moves in relation to a vertical axis (Sommerfreund & Masse, 1995). Tilt was an option not really available until the 1990s. Power tilt in space is now a commonly used seat function to assist with transferring into the wheelchair. Tilt can be forward or back. Backwards tilt increases stability in sitting by preventing a person from falling forward while travelling down inclines; it can also be used to increase comfort and to facilitate rest (Aissaoui, Lacoste & Dansereau, 2001; Engstrom, 2002; Ward, 1994). Tilt also gives pressure relief (Henderson, Price, Brandstater & Mandac 1994; Hobson & Crane, 1992).

Expert clinical opinion listed many reasons for the use of tilt including, poor upright sitting position tolerance, a need for frequent change of position, a fixed kyphosis, poor/weak head and/or trunk control, low or high tone, a poor tolerance of aggressive positioning, limited hip flexion, sleeping for an extended period of time secondary to medical problems, and for pressure relief (Pfaff, 1993). Tilt allows gravitational postural realignment to help reduce collapsing deformities of the spine (Trefler & Schmeler, 2001). Postural deformities can then impact on physiological function (Stewart, 1991). However a supported upright sitting position as opposed to tilted has been deemed important for swallowing and reducing aspiration (West & Redstone, 2004). Therefore meeting wheelchair and seating needs can be a fine balance.

Dewey et al. (2004) compared the experiences of tilt in space wheelchair use to conventional wheelchair use in British clients with severe multiple sclerosis. The majority of the clients in the study reported increased comfort and many other benefits such as being able to sit for prolonged periods, improved postural support and stability; and the ability to maintain a ninety degree hip position to inhibit spasticity. However, it should be noted that this study also included manual wheelchair users.

The literature has focussed more on the physical benefits of tilt and this has not been translated into the specific occupational outcomes for individuals and how tilt supports occupational engagement within the user's environment.

Power seat high low function

The power elevation or high low seat function allows the wheelchair seat unit to be raised or lowered. The RESNA (Arva, Schmeler, Lange & Lipka, 2005) position statement on seat elevating devices for wheelchair users used expert clinical opinion and evidence from the literature to state the view that seat elevators are often necessary for individuals to accomplish mobility related tasks of daily living that require reaching, to facilitate transfers to surfaces of various heights, and to change the height of a person to enhance interpersonal communication. Seat elevation was found to be primarily used to complete activities of daily living in a study using an electronic seat logger (Ding et al., 2008). The function of an adjustable seat height is also effective in assisting with transferring to different heights (Lee & Lee, 2000; Greene & Roberts, 2005). This information demonstrates a number of uses, allowing a match with environmental demands that assume standing as a position for occupations.

Power reclining backrest function

Reclining a wheelchair backrest is a way of shifting weight and a person's centre of gravity backwards therefore recline is more stable on a heavy power wheelchair base. Recline occurs when the angle between the back and the seat is greater than 90 degrees (Sommerfeund & Masse, 1995). Expert clinical opinion listed many reasons for using recline, mainly for user stability, rest and comfort (Greene & Roberts, 2005; Lange, 2001; Pfaff, 1993). Recline can also prevent a person from falling forward (Engstrom, 2002). It is also used to accommodate the following: limited hip flexion range, fixed kyphosis, and low muscle tone. Recline can also meet the need for frequent back angle changes; reduce transfers in and out for rest; manage fatigue, and meet medical needs to be slowly brought upright (for example to manage hypotension). A user may also sleep in the wheelchair for extended periods of time secondary to medical problems, and for pressure relief (Pfaff, 1993). Intermittent catheterization or catheter drainage can be easier in a reclined position. However it must be noted that recline cannot be effectively used when there are extensor range of motion limitations at the hip joint (Lange, 2000).

A Swedish study found clients reported a reduction in seating discomfort and back pain following wheelchair seating intervention that involved a change in back angle (Samuelsson, et al., 2001). Although the clients were mainly manual wheelchair users, the study does show that back angle can increase comfort. Similarly, a study of users with muscular dystrophy suggests recline offers a means of stretching the hip joint which will help to reduce fixed hip contractures and increase

comfort (Richardson & Frank, 2009). This raises the question: what are users' experiences of using power recline on a multifunction power wheelchair?

Power elevating leg rest function

The RESNA (Diciano et al., 2009) position statement on power elevating leg rests for wheelchair users used expert clinical opinion and evidence from the literature to state the position that power elevating leg rests can be used to manage oedema because the legs of wheelchair users may accumulate fluid. Elevation of the legs above the level of the heart by about 30 cm is generally recommended as part of the management of oedema in conjunction with other measures such as support stockings. Elevating leg rests are most effective when used in combination with tilt to allow elevation of the legs above heart level. Elevating leg rests may also help in reducing feet and ischial pressure and can help reduce shear (friction of skin and bone moving on a surface) along the seating surface. Again this raises the question: what are users' experiences of using power elevating leg rests?

Power standing function

A standing wheelchair brings the user into a standing position from sitting without having to get out of their wheelchair. The first standing wheelchair was developed in 1975 by LEVO (Raber, 2010). Standing wheelchairs are reported to have many physiological and functional benefits for users as it enables hands free passive standing, pressure relief, psychosocial well-being, and extends the person's functional reach (Meyer, 2010). The RESNA position statement on the application of wheelchair standing devices provides some supportive evidence and shares clinical applications (Arva et al., 2009). Passive standing has been shown to counteract many of the effects of a chronic seated posture and long-term immobilisation in users with spinal cord lesions including bone demineralization, urinary calculi, cardiovascular instability, reduced range of motion and muscular tone, spasticity, joint contractures and postural deviations (Gear, Suber, Neal, Nguyen & Edilich, 1999). Passive standing has been shown to reduce the decline of calcium secretion (Issekutz, Blizzard, & Rodahl, 1966; Kaplan, Roden & Gilbert, 1982). The metabolic rate in standing is also twice what it is in sitting (Ainsworth et. al., 2000) which would assist with respiration and circulation. Shields and Dudley-Javoroski (2005) studied the standing patterns and satisfaction of an individual user with paraplegia who reported a standing wheelchair gave him the ability to participate in dart throwing, to assist with household tasks a well as improved bowel motility and spasticity. Funding has been found to be a block to the more wide

spread use of standing wheelchairs (Kreutz, 2000). Overall little research was found on the experience of users of the power stand function.

Combined power functions

The combined use of tilt, recline, and seat elevate functions in multifunction power wheelchairs have been quantitatively researched in America using a specially designed portable seat function data logger. The objective measure of the usage patterns of adults with physical disabilities who used multifunction power wheelchairs showed that the functions were consistently used throughout the day and people spent most of their time in a tilted and/or reclined positions. People spent little time in a fully upright position and small tilt and recline angles were used, suggesting they were used more for posture and comfort than pressure relief in order to increase the length of time they sat in the wheelchair (Ding et al., 2008). The ability to sit for longer periods of time was also mentioned in other studies (Dewey et al., 2004). Considerations for comfort suggested by a consumer panel of users (Batavia & Hammer, 1990) were as follows:

Does the device cause pain or discomfort?

Does it make noises or sensations that are irritating?

Does the consumer have to strain physically to use the device?

Is it physically compatible with the consumer's body?

Does the device have special features to enhance comfort for example suspension?

Comfort has been raised as an important issue in other studies as well (Weiss-Lambrou et al., 1999). Electronic logging of use and location showed that power wheelchair usage is very individual and complex (Sonenblum, Sprigle, Harris & Maurer, 2008) for example frequent usage throughout the day. Ward et al., (2010) also surveyed the use of multiple functions in adults with motor neurone disease and found all the functions were used on a daily basis. Tilt and recline features provide the most pressure relief when used in combination (Aissaoui et al, 2001; Vaisbuch, Meyer & Weiss, 2000). However, there is little qualitative data included with these studies to clarify the findings from the users' perspective, which is the focus of this research paper.

Wheelchair assessment and provision

Lastly, the literature also focussed on the process of assessment and provision of wheelchair and seating. Many occupational therapists are involved in this area of work as evidenced by the

number of peer reviewed articles found. Occupational therapists are involved in wheelchair and seating specialist practice because initially mobility and/or positioning present a challenge to occupational engagement and secondly wheelchair and seating are part of a solution that can enable occupation. These are the first two of five essential elements of occupational therapy practice identified by Polatajko, Davis, Cantin, Dubouloz-Wilner & Trentham (2007). The third element is client centred, client specific goals (this is the voice of the client); the fourth, a broad multidisciplinary knowledge base underlies practice because of the complexity of human occupation (for example the knowledge of many disciplines have been drawn on in this literature review); lastly, the fifth element is a complex reasoning process, based on enabling occupation needs. Thus occupational therapy needs to be occupational in nature (Fortune, 2000; Hocking, 2001; Molineux, 2001, 2004; Wilding & Whiteford, 2007) as well as person- centred (Wright-St Clair & Seedhouse, 2005).

A key focus of wheelchair and seating assessment is the comprehensive evaluation of a person's needs within their environments as stated frequently in the literature (Auger, Demers, Gelinas, Miller, Jutai, Noreau & Depa, 2010; Batavia, 1998; Bergen, 1998; Cutler Lewis, 2003; Di Marco, Gagnon, Noreau & Vincent, 2005; Heberg-Kristensson et al, 2006; Kettle, Rowley & Chamberlain, 1992; Pain, McLellan & Gore, 2003; Samuelsson, Larsson & Thyberg, 1999; Taylor, 1993; White, 2003). Di Marco, Russell and Masters (2003) also stress the importance of on-going, regular assessments or reviews of people's wheelchair and seating needs because people's needs and environments can change. Mills et al. (2001) developed and researched an assessment based on an adapted version of the Canadian Occupational Performance Measure (COPM) (Law et al., 2005) called the Functional Evaluation in a Wheelchair instrument (FEW). Consumers in the preliminary studies identified accessing task surfaces, transfers, transportation, accessories and architectural barriers as some of the categories to be considered. The Power-Mobility Community Driving Assessment (PCDA) is a useful comprehensive assessment which looks at the person, power wheelchair, driving skills and specific environments (Letts, Dawson, Masters, & Robbins, 2003). The Wheelchair Outcome Measure (WhOM), also based on the COPM (Law et al., 2005), is an assessment tool that gives users a strong voice by focussing on person centred outcomes and satisfaction at a participation level (Mortenson, Miller & Miller-Pogar, 2007; Mortenson, Miller &Auger, 2008) and therefore could be considered for wider use.

When assessing personal mobility, there is always more than one challenge being addressed and assessment should not be limited to a static situation, for instance a "perfect" aligned sitting position. Rather, it should include the effects of engaging in daily living activities on posture, and the effect of changing posture on the client's functional abilities (Andrew et al., 1993). In other words, occupational therapy assessments should be dynamic and include the interaction between person, occupation and environment, thus being true to the philosophy of occupational therapy (Radomski, 1995, Law et al, 1996). Scherer (1996) commented that whilst services are very aware of the physical needs of individuals, there is often less attention given to the social and psychological aspects of use, which is another area of complexity. For example using a multifunction power wheelchair that cannot fit under the family's dining room table (personal communication from client) thereby impacting on the person's ability to engage in family mealtimes. Exploring people's experiences of using power wheelchairs in their everyday lives should shed light on individual aspects of use. Therefore the assessment of powered mobility is complex.

Complex needs require complex solutions and multifunction power wheelchairs fall into this category. Ripat and Booth (2005) researched the service delivery model preferred by stakeholders. This resulted in a range of recommendations including the importance of participation of the user throughout the process, the need to trial in the environments of use, the consideration of future needs and the opportunity to try new technology. For example: computing with the power wheelchair (Wilkins, Livingstone, 2011). In addition, 'effectiveness' was identified as an important criterion by a panel of consumers (Batavia & Hammer, 1990). 'Effectiveness' is defined as "the extent to which the functioning of the device improves the consumer's living situation, as perceived by the consumer, including whether it enhances functional capacity and/or independence" (p.431). Winance (2006) proposes that through the effective use of a wheelchair the body of a person as it relates to the world is transformed and through these actions 'embodiment' of the wheelchair and the person occurs. Trying out wheelchairs can make it apparent that the relationship between a person and a wheelchair is not easy (p.54) hence the importance of an authentic occupation based practice (Polatajko, Craik, Davis, & Townsend, 2007) informed by the user's voice.

Wheelchair provision can impact on all areas of life because of the integral nature of mobility and accessibility within the environmental context. White and Lemmer (1998) used integrated

methodology to survey 125 therapists and 130 service users in Britain to look at factors that contribute to effective wheelchair provision. These included in depth and knowledgeable therapist assessment, good communication and allowing shared control with users in decision making. By giving clients a 'voice', better outcomes can then be achieved. For instance, a large UK survey of wheelchair use and preferences of people with spinal cord injury highlighted the importance of appropriate provision (Rose & Ferguson-Pell, 2002). Moreover, international standards support clinician skills and judgement as an effective system for matching equipment to an individual's needs (Ferguson-Pell et al., 2005).

Cowan and Turner-Smith's (1999) UK survey of people who use electronic assistive technology including powered wheelchairs showed that the majority of equipment was used regularly. However sixty percent of the 135 respondents reported a problem with the provision process such as funding issues, information availability, maintenance, and training. Mortenson and Miller (2008) researched the perspectives of 14 wheelchair users, 7 of their associates and 13 prescribers regarding the provision process. One of the key messages is that occupational therapists need to evaluate their role carefully so they are not a barrier to occupational engagement, use outcome measures to measure effectiveness and advocate for accessibility and funding issues. Sprigle and Lenker (2011) emphasised the importance of cooperation and effective links between services. Activities of the suppliers of mobility devices were logged revealing there were many activities from preparation, to delivery and setup of trials, to ordering, to delivery and final setup and follow-ups. This must all impact on the users' experiences and therefore giving them the opportunity to voice their perspectives is important.

In relation to wheelchair provision, 'affordability' was identified as important by Batavia and Hammer's (1990) consumer panel. 'Affordability' is defined as "the extent to which the purchase, maintenance, and/or repair of the device causes financial difficulty or hardship to the consumer" (p.430). Related factors also included the initial price of the multifunction power wheelchair; hidden costs such as additional components above base cost; repair costs; total costs, and warranties. There is a need to increase the affordability of technology to enable greater, equitable access to the benefits (Scherer, 1996). Neri and Kroll (2003) found that the consequences of financial barriers to accessing and affording healthcare affected all aspects of life including social, psychological, physical, economic, and independence for American adults with disabilities. Subsequently consumers may need a particular type of wheelchair but if

economic, social and political factors don't permit funding it is removed as a choice. This is supported by the results of an American survey of 412 people with spinal cord injury (SCI) which concluded people who are socioeconomically disadvantaged would be less likely to receive customisable wheelchairs (Hunt et al, 2004). In the light of this information it will be useful to consider New Zealand users' experiences as funding is publically available.

Overall user satisfaction and improved quality of life is an important consideration and so user feedback needs to be sought otherwise professional practice can remain unchallenged and based on assumptions (Weiss-Lambrou et al., 1999; Zhan, 1992). For example there is some evidence that there is a disparity in wheelchair prescription between different diagnostic groups despite a similarity in wheelchair need (Ambrosio et al., 2007). This is an important consideration to follow-up in the New Zealand context. The Quebec User Evaluation of Satisfaction with assistive Technology (QUEST 2.0) was developed to assess consumer satisfaction and tested by panels of stakeholders and consumers (Demers, Weiss-Lambrou & Ska, 2002). The QUEST 2.0 covers both device and services component for example, questions about satisfaction with the dimensions of the device and the repairs and servicing. Researchers used a cross sectional design study (incorporating the QUEST 2.0) of mobility device users in Sweden which indicated satisfaction with the service was lower than satisfaction with the device and follow-up was an area that needed to be improved (Wressle & Samuelsson, 2004). Follow-up or 'the process of adjustment' is important work for 'creating new possibilities of action' for the person (Winance, 2006, p. 52). Failure to consider user perspectives and experiences is often associated with poorer outcomes or even 'abandonment' of assistive devices (Batavia & Hammer, 1990; Gillen, 2002; Wielandt & Strong, 2000). Therefore valuing and amplifying the users' voice in assessment as well as in research is important. New Zealand needs to develop a best practice protocol for wheelchair assessment.

Literature review conclusion

In-order to inform and provide context to this study a literature review was conducted to identify the functions and considerations related to power wheelchairs. The literature revealed that there are many benefits to power wheelchair mobility such as: increased mobility, comfort, participation, positive feelings of freedom, self-confidence, and purpose. There were also many options to consider, including the type of power wheelchair base and the power functions

required. Many other considerations suggested by a consumer panel (Batavia & Hammer, 1990) such as 'usability' and 'repairability' need on-going research because of developments in technology. Much of the research was identified from the perspective of the discipline of the various researchers rather than the voice of the users. Occupational therapists, because of their role in assessing and recommending wheelchair solutions, often consider themselves as providing an important link between the users and the acquisition and use of technology (Cowan & Turner-Smith, 1999; May & Rugg, 2010; Scherer, Sax, Vanbiervliet, Cushman & Scherer, 2005). It is evident that missing is a focus on adult users' perspectives and experiences of using their multifunction power wheelchairs. The literature reviewed does not give users adequate voice. Therefore the focus of this study is to elucidate New Zealand adults' experiences and perspectives of using their multifunction power wheelchairs, by giving them a 'voice'. Descriptive information gathered in this study will be around contextual daily experiences, occupational performance and positive and problematic aspects of use to inform assessment and provision.

The next introduces and describes the study methodology.

Chapter 3: Methodology

Introduction to methodology

In order to research adult users' perspectives and experiences of using their multifunction power wheelchairs it was important to consider which research methodology would be the most appropriate. The purpose of the research was identified as being to collect descriptive information from individuals using multifunction power wheelchairs. Accordingly a qualitative descriptive methodology was used in line with Sandelowski's thinking (2000; 2010), which allows for "straight descriptions of the phenomena" (p. 334). This methodology allows me to describe and understand the perspectives of the participants and the meaning and context in which their everyday experiences occur (Braun & Clarke, 2006; Miles & Huberman, 1994).

The qualitative research worldview or naturalistic paradigm contains three important elements with which to provide justification for the choice of research methods. These are ontology, epistemology and methodology (Denzin & Lincoln, 2005). According to Crotty (1998), 'ontology' is concerned with what things there are in the world to know or "what is;" 'epistemology' is the theory of what we know and "how we know what we know;" 'methodology' is "the plan of action" which links the choice of methods to the desired outcome, and the 'method' is the actual process of gathering and then analysing the data related to the research question (pp. 2-10).

Qualitative descriptive research involves the exploration of an issue in depth, with an emphasis on seeking information from the people who are experiencing it. Therefore detailed rich data was gathered from a small number of participants (Saratakos, 1998). Multifunction wheelchair users are well positioned informants as to what works, what does not work, and what needs to be changed in relation to their everyday lives (Robeiro, 2000). Subsequently a carefully considered combination of sampling and data collection method was used (Sandelowski, 2000) to capture participants' voices.

Qualitative descriptive research was therefore selected as the most suitable and pragmatic option to achieve the goal of this research (McPherson & Lord, 2000). Qualitative descriptive research is

described as level one exploratory research, designed to document descriptions about a particular topic compared to level two research which focuses on the relationship between variables, and level three research which examines the cause and effect of a relationship (Patton, 2002; Sandelowski, 2000). However the construction of evidence should be considered as a continuum rather than a hierarchy with an emphasis on the best research type to answer the question (Humphris, 2000). In qualitative descriptive research the language is a means of communication (Sandelowski, 2000). Here, language refers to the 'voice' of users of multifunction powered wheelchairs. This allows for the direct description and interpretation of participants' perspectives and experiences in order to contribute to a knowledge base that can be built on by other research. The descriptions this research study provides are dependent on those that are provided by the participants and what I, as the researcher, selected to describe (Sandelowski, 2000). Hence the researcher is part of the research process and I need to consider my background and experience.

Research Approach – Theoretical Underpinnings

Underpinning this study is a social constructionist epistemology which recognises that personal, social and cultural meanings are built up or constructed (Mattingly & Flemming, 1994). Social constructionism is a relativist standpoint (Crotty, 1998). Constructionism is " the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context" (Crotty, 1998, p. 42). Data derived from social constructionist inquiry represents another construction to be taken into account in the move towards consensus of knowledge. This seems a particularly useful approach for this study as it aims to describe adults' perspectives and experiences of using multifunction power wheelchairs, which could be added to over time. This is in contrast to constructivism which is "the meaning-making activity of the individual mind" (Crotty, 1998, p. 58).

The ontological perspective used in this study is relativism. Relativism recognised that each of the participants created their own reality and so there can be multiple realities. Therefore, when a participant described something in the study, it was in the context of that individual's environment (Patton, 2002) and personal reality. Based on this ontological framework, it was expected that participants would have different backgrounds that would contribute to their different described perspectives and experiences, for example different to the therapists doing the

wheelchair prescribing. Relativism asks us to take into account the human condition (Drummond, 2005), people's humanity. Thus the voices of the users of multifunction powered mobility in this study, were real to them and offered rich insights into the way things were for them (Crotty, 1998), thereby providing therapists and others with meanings to inform practice. That is, "we need to recognise that different people may well inhabit ... different worlds" (Crotty, 1998, p. 64). Table 2 summarises the methodology used in this study.

Table 2: Summary of constructs and approaches used in the study

Construct	Definition of Construct	Research Approach
Methodology	How knowledge can be gained	Qualitative descriptive
Paradigm	Set of beliefs	Naturalistic
Ontology	What is	Relativism
Epistemology	How we know what we know	Social Constructionist
Method	Process to gather data	Individual semi-structured interviews

Research method

There are a range of methods of data collection that can be used under qualitative descriptive methodology. Focus groups were initially considered but the disadvantages of limited response time for each individual present, the inability to assure confidentiality with more than one participant present, controversial or personal issues not being able to be discussed, and the fact the group would not be in a natural setting were considered to be significant issues (Patton, 2002). Therefore the method of data collection used in this study was individual semi-structured interviews in participants' own environments. Open ended questions were developed to guide the interview process and care was taken to eliminate any personal ideas or influence that might have shaped the information provided by the participants. Patton (2002) recommends that a semi structured approach to interviewing is used by novice researchers (like me as a first-time post-graduate student researcher), to reduce the likelihood of leading questions and interviewer effects. The questions were submitted along with the research protocol for ethical approval.

Ethics

Ethics is a central part of the research process and is the "philosophical study of the moral value of human conduct and of the rules and principles that ought to govern it" (Hanks, 1979, p.502). Ethical approval was sought prior to commencing the study. Ethical approval, reference NTX/10/EXP/213, was granted by the Chairperson of the Northern X Regional Ethics Committee under delegated authority on the 2 November 2010 (Refer Appendix 3).

Informed Consent

The background information sheet and consent forms (See Appendix 6) were provided to all the participants who volunteered and met the inclusion criteria (Refer page 26). A week later, after the participants had had time to receive and read the information posted, they were contacted by phone to discuss the information provided, answer any questions, to confirm their consent to participate and to arrange a time and place to meet. The signed consent forms were collected prior to commencement of the interviews. A copy of the consent form was given to the participant to keep.

Withdrawal

It was emphasised that participation was voluntary with freedom to totally withdraw or to not answer a question at any time. Participants could choose to terminate the interview at any point or to request to stop the audio recorder. No participants withdrew but one participant did ask for some very personal information not to be recorded.

Confidentiality

To ensure confidentiality participants remained anonymous to everyone except to me as the researcher. No directly identifying information was used in any reports or discussions. Participants were linked to the number in the sequence of interviews carried out and each statement was numbered in order of their occurrence in the interview, and these were used for coding. The Privacy Act (New Zealand Government, 1993) and the Health Information Privacy Code were adhered to and all personal information was treated as confidential. Field notes and transcripts were stored securely in a locked filing cabinet.

Potential risks to participants

This was considered low risk research for participants as it was confidential one to one interviews. It was not my intent to create wish lists with clients, or to provide information about the range of equipment available unless specifically requested, or to critique other therapists'

work in any form. I disclosed my background as an occupational therapist and my places of work in the public and private sector.

Cultural considerations

The research acknowledged the principles of Te Tiriti Waitangi (Orange, 1987) and Tikanga Maori. The principles of participation, partnership and protection were honoured through engagement and consultation with the Chief Advisor of Tikanga Maori, Auckland District Health Board. The ethics application was reviewed by the Chief Advisor and all feedback acted upon (Mata Forbes, personal communication, October 10, 2010). For example, an interpreter should be offered and every conceivable effort should be made to ensure the Treaty of Waitangi principles are adhered to within the research project. Whilst there were no Maori participants in this study, it was important to ensure potential tangata mauiui (Maori consumers) were not disadvantaged (Rochford, 2004).

I am a New Zealand Pakeha (European), therefore consultation with an appropriate peer reviewer was planned if a participant self-identified as Maori or self-identified as from another culture. The research and thesis is presented in the English language. An interpreter would have been offered if requested or required but this was not necessary. Unfortunately despite extensive advertising via all possible networks there were no Maori participants and all ten participants identified as New Zealand European.

Participants

Following the granting of ethical approval participants were invited to take part in the study via word of mouth and written advertising (Refer Appendix 5) throughout the Auckland disability networks and organisations. Contact could be made via face to face, email, telephone or post. The majority of responses were by email and only two phone calls were received. Telephone contact was made to all participants to thank them for their interest, and check criteria for inclusion. Once suitability was confirmed, general availability for participation, personal and cultural requirements, and a contact address for information to be mailed was obtained.

Sampling & size

Once ethical approval was granted convenience sampling was used to select participants who had met the inclusion criteria (Berg, 2001; Devers & Frankel, 2000). Convenience sampling was used

to be as inclusive as possible and because the group may be difficult to access because of the significant nature of their disabilities. Only ten people (n =10) actually made contact with the researcher although poster, email and word of mouth advertising continued for more than 6 months. It was decided that due to the in-depth nature of the interviews and the rich data collected from the 10 participants the sample size was adequate. This participant number is similar to other qualitative research studies that have yielded rich interview information. Wheelchair users sometimes require further time and training to get used to equipment and to resolve any setup issues. Therefore although I acknowledge the need for prospective studies this would also have been impractical with the then available resources and would have led to extended timeframes for the size of the research. Some of the participants in this study and other studies reviewed had deteriorating or progressive conditions which makes self-reporting a useful way to evaluate effectiveness (Dewey, Rice-Oxley & Dean, 2004).

Inclusion criteria

The ten participants met the following inclusion criteria:

- Adult (16 years and older).
- Long term permanent physical disability.
- Current fulltime user of a multifunction power wheelchair (A minimum of 6 months use required so there are experiences to share).
- Resident in the Auckland region (Availability required to meet for face to face interview).
- Ability to communicate independently (so own words can be used).

Exclusion criteria

Those groups excluded were:

- Children, as they have specific developmental needs, are a unique population group and worthy of research in their own right.
- People who were recent (less than five years) and current clients I had worked with so there was no role confusion or power imbalance in the research relationship.
- People who had any significant cognitive, communication, psychological or acute medical impairments that would prevent voluntary participation in the study.

Data Collection

Semi structured, open ended individual interviews were used as the main data collection tool. This allowed participants to discuss their experiences according to their own level of disclosure (Patton, 2002).

Interview

An interview guide (Refer Appendix 4) was developed from categories identified in the literature review. The use of an interview guide allowed the interviewer to commence with background, contextual information as a starting point and introduction, for example "could you explain the nature of your disability… and the background to how you came to get a multifunction power wheelchair?" Guba and Lincoln (1989) state "the context provides the "surround" within which the persons forming the constructions live and of which they try to make sense (page 8)." The conversation was then built with further questions to illuminate the participant's experiences and perspectives (Patton, 2002). The interview questions were open and semi structured to focus on topics of interest to the participant and allowed flexibility to explore these responses, for example "What is your life like using a multifunction power wheelchair?" Semi structured interviewing was the primary process of data collection for this study because it facilitated in-depth discussion and allowed the participants to disclose experiences and perspectives to their own level of comfort (DePoy & Gitlin, 2005; Patton, 2002).

The interview was practiced through role play with the academic supervisor, and also checked and discussed with two expert users of multifunction power wheelchairs (who were not able to be included in the study because they were recent clients) prior to commencement of the research. This was an informal pilot of the questions so they could be practiced, reviewed and appropriate changes made.

The face to face interviews were approximately one to two hours in duration. Each interview began with an explanation of the consent process and the signing of the consent form if the participant wished to proceed. A flexible time frame allowed for breaks if fatigue was an issue or for extra time for participants to fully express their personal perspective.

The time and location was arranged in accordance with the participants' wishes. Interviewing occurred within the participants' home or work environments to help maintain privacy, to ensure

a natural environment, to reduce any anxiety about being interviewed, and to reduce any fatigue or other costs involved with travel. Three of the clients were interviewed in their workplaces in private offices and seven clients were interviewed in their homes.

All participants received a thank you, koha (gift) in the form of a voucher after the interviews were concluded. A thank you letter and a copy of the summary of findings were posted at the completion of the research.

The interviewing was audio recorded (with the participants' permission) and transcribed verbatim as soon as possible following the completed interview to ensure reliability of the data (Refer Appendix 7 for an example of a transcript). The transcripts were checked against the audio tapes for accuracy. I also used note writing to write down key phrases or points. Field notes generated immediately after the interview allowed for consideration of contextual information (Berg, 2001).

Copies of the transcripts and data analysis were returned to the participants for checking and clarification and no changes were requested. A further interview of approximately one hour was planned if any changes were suggested or requested by the participants but this was not required. All the interviews were recorded clearly and were able to be accurately and easily transcribed. Sufficient richness of data was available for analysis.

Trustworthiness

Trustworthiness or rigour is a major consideration in the design of a qualitative study (Krefting, 1991). Guba and Lincoln (Guba, 1981; Guba & Lincoln, 1985) proposed the terms "truth value" (credibility), "applicability" (transferability), "consistency" (dependability), and "neutrality" (confirmability) (p. 289 - 357) be used as the qualitative equivalents for internal validity, external validity, reliability and objectivity.

Credibility was attended to through acknowledging that my prior knowledge and experience of wheelchairs and seating may have led to set ideas and assumptions prior to embarking on the study, for example my thoughts about the effectiveness of various power wheelchair functions. However through consciously undertaking the role of a learner (as opposed to therapist) and asking the participants as the experts to share their experiences real insights have been gained into the use of multifunction power wheelchairs on their lives. My interest and experience in the

field has assisted in my understanding of the participants. Transcripts were returned to all the participants for member checking of accuracy.

Transferability was addressed through use of detailed description of the demographic data, inclusion and exclusion criteria were observed, and through convenience sampling a varied group of adults participated. This detail allows readers to assess and judge how transferable the findings are.

Dependability was demonstrated through following auditable research methods and ensuring I participated in on-going academic supervision to ensure consistency and integrity of the research process. Data was coded and recoded to check consistency of results.

Confirmability is evident through examples of the records in the appendices. Reflections were recorded in a personal journal and the use of field notes during interviews to increase trustworthiness (Carpenter & Hammell, 2000) and reflexivity (Finlay, 1998; Primeau, 2003). The influence of my own background, values and ideas were discussed with my supervisor regularly.

Data Analysis

The first stage of data analysis began during information gathering and was primarily inductive in that the themes identified were from the data. Analysis was data driven (Patton, 1990), in other words starting with the details of the participants' experiences and perspectives and moving to a collective voice. The data analysis process was assisted by my direct interviewing, field notes and transcribing. All verbal and nonverbal utterances were recorded (Refer Appendix 7 for an example of a transcription). Both descriptive validity (the accurate accounting of events), and interpretive validity (the accurate account of the meanings participants attributed to the experience) were sought in the research (Sandelowski, 2000, 2010). The processes of data analysis outlined in the qualitative description literature were considered and followed where they fitted the nature of the study (Braun & Clarke, 2006; Dickie, 2003; Miles & Huberman, 1994; Neergaard, Olesen, Anderson & Sondergaard, 2009; Sullivan-Bolyai, Bova & Harper, 2005). Transcribing completed the first stage of the data analysis.

To gain an overall impression of the content, the recordings and transcripts of all the study interviews were reviewed repeatedly before, and during the coding. This was to assist familiarity

with the data and to generate initial codes. This was stage two data analysis (Refer Appendix 8 for an example). Although the use of a software programme (such as NVivo) was considered, it was not readily available; therefore the coding was done manually. Each data item was given equal attention during the coding process. Initially 253 key statements were identified as relevant to the research question. The participants' presentations of their experiences and perspectives of their multifunction power wheelchair use were used for detailed direct description, rather than in-depth interpretation during data analysis.

Qualitative thematic analysis used inductive thinking processes to discover recurring, repeated, meaningful patterns descriptive of the question being researched (Auerbach & Silverstein, 2003; DePoy & Gitlin, 2005, Owen, 1984). All the data was organized into groups of repeating ideas (themes) without paying attention to themes that previous research may have identified, using a different colours to highlight different themes.

Stage three of the analysis occurred once initial themes had been identified (Refer Appendix 9 for an example). All conversations that fitted within that theme were compared, triangulated and categorised. As required throughout this process new categories were formed. Visual representations such as the use of graphs, mind-maps and colours were used to identify overarching themes and subthemes. The analysis was a recursive process, where movement was to and fro, between the different stages.

Stage four involved reviewing the themes. This involved checking there was enough data to support each theme, and that the meanings and associations in the whole data set were accurately presented (Owen, 1984). This stage could have continued for an extended period of time, so a satisfactory end point had to be identified with the support of my primary research supervisor (Sian Griffiths, personal communications).

Stage five was the final refining, defining and naming of the themes as presented in the findings chapter. To maintain confirmability all the transcripts, analysis and drafts of the report were provided to, and discussed with, my supervisors throughout the process. I aimed to describe and interpret the findings maintaining empathetic neutrality (Patton, 2002). Producing this written report was the sixth and final stage, as the process of writing helped further clarify and refine my understanding of the findings (Savin-Baden & Fisher, 2002).

Methodology summary

In-order to answer the research question the methodology chosen was qualitative descriptive and the method used was individual, semi structured interviews. The ethical issues were considered including informed consent, freedom to withdraw, confidentiality, potential risks and cultural considerations. The process for data analysis is provided in detail to facilitate understanding of the data and any future replication.

Chapter 4 now presents the findings.

Chapter 4: Findings

Introduction

Many experiences and perspectives of using multifunction power wheelchairs were shared by the participants. This chapter will firstly present the general demographics of the participants and then their statements under the identified themes will be presented.

Participant Characteristics

There were five male and five female participants, all urban community dwellers who live in Auckland. There were two participants in each of the following age brackets: 20 to 30, 30 to 40 and 40 to 50 years respectively, one in the 50 to 60 year age bracket and three in the 60 to 70 year age bracket. Due to the small population of Aotearoa, New Zealand, characterised by small interconnected communities it was decided the demographics of individual participants could not be used. The following table demonstrates the range multifunction power wheelchair functions used (Refer Table 3). Tilt was most common function used by nine participants, eight participants used recline, seven participants used seat high low, and five participants used elevating leg rests. The majority of the wheelchairs were midwheel drive (MWD) bases, only two wheelchairs being rear wheel drive (RWD) and one being four wheel drive (4x4).

Table 3: Multifunction power wheelchair functions used (N=10)

Interview number	Tilt	Recline	Seat high low	Stand	Elevating Leg rests	4x4	MWD	RWD
1	x	x	x		x	x		x
2	x		x				x	
3	x		x				x	
4	x	x	x				x	
5	x	x			x		x	
6	x	x	x				x	
7		x		x				x
8	x	x	x		x		x	
9	x	x			x		x	
10	x	x	x		x		x	

Notes: X: indicates functions used. 4x4: 4 wheel drive.

MWD: midwheeldrive. RWD: rear wheel drive

General medical diagnoses (refer Table 4), and backgrounds (refer Table 5) of the participants are now presented. This shows that this is a newer group of users with a higher level of impairment now active in the community. The range is broad which contributed to the richness of the data collected.

Table 4: General medical diagnoses (N=10)

General diagnosis	Number of participants
Amputee	2
Neuromuscular	4
Multiple sclerosis	1
Polio, stroke	1
Spinal cord injury, tetraplegia	3

N. B. There is a difference between a diagnosis and how someone might live with it so it does not define someone. Also note some diagnostic groups are not represented such as people with cerebral palsy.

Table 5: General background of participants (N=10)

Background	Number of participants
Single	5
In relationship	5
Parent of dependent children	2
Part time worker	3
Full time worker	2
Retired	4
Student	1

Summary

The demographic data presented suggests the convenience sample encompassed a diverse and heterogeneous group of adults. Although this is hardly surprising as disability affects the full spectrum of society, and equipment was publicly funded in New Zealand at the time of the study and funding did not differentiate or discriminate on the basis of socioeconomic background.

Key Themes

Following the principles of a thematic data analysis process (refer Data Analysis, p.29) six key themes were identified that were seen to encompass the common experiences and perspectives of the participants. Each key theme will be introduced and described further, supported by the use of direct illustrative quotes. Whilst the findings of the study are described under theme headings, it should be noted that the themes are interrelated and therefore most quotes were considered under more than one theme heading. I used judgement and discretion to determine which theme the quote most closely and accurately represented. The quotes are italicised and the interview number and sentence number are in brackets at the end of each quote. For example *(1-1)* would mean the first interview and the first statement. Therefore in answering the research question which considered what are the perspectives and experiences of adults using multifunction power wheelchairs the following six key themes and related sub-themes were identified:

1. Importance of mobility
    - Improved mobility
    - Barriers to mobility
2. Environmental factors affecting mobility
    - Home
    - School and Work
    - Outdoors
    - Transport Issues
3. Benefits of power functions
    - General benefits
    - Tilt function
    - Recline function
    - High low function
    - Elevating leg rests function
    - Standing function
4. Importance of independence
    - Increased independence
    - Social Independence
    - Barriers to Independence

5. Personal and social identity
6. Well-living

Theme 1: Importance of Mobility

Participants reported a range of mobility experiences and interestingly half were positive and half were negative experiences suggesting that multifunction power wheelchair use can have benefits as well as challenges. *Getting out everywhere, getting out with my family, places I couldn't go before because there was no way for me to get there (9-5).*

Improved mobility

All participants experienced general improved mobility especially where they had been struggling with walking, using crutches or self-propelling a manual wheelchair and then transitioned to a power wheelchair: *Power chair very good, because before I was on crutches all the time and then went to manual chair but because of shoulders very hard to use, so then I had bad experience with walking… (6-1). My rotator cuffs stopped working because I just get out and do what I want to do so to save my shoulders I got a power chair (1-1).* Independence in general mobility and reducing reliance on others to push them was important. *I would have to be pushed around by a family member or someone; they weren't always available to push me around in the manual wheelchair so the power chair has been a life saver to me (9-6).*

Improved reliability and drive quality and power were experienced: *This chair is just fine and I never feel it is not going to make it up somewhere. It is quite reassuring to think it is going to get you there (2-24). The chair has made a big difference in the smoothness of my ride; it is more comfortable (8-6). This one is a lot more powerful and the battery seems to last well (2-3).* Safety was enhanced… *this chair enables you to do things and gives you a lot more comfort. Feel a lot more safer, just enjoy being out there more, it's the quality, and it is nice… (1-21).*There was the ability to move faster which could even make it difficult for other people who are walking to keep up: *If I do go out, for instance into town, I leave everybody for dead, the speed I can go. Yeah! Nobody can keep up with me (3-6).* This participant enjoyed the speed and freedom.

Safety and stability were also important: *For people that are less mobile than me this 4x4 is a really safe chair, like I said I have worked with people with disabilities and I have been out with*

them and they are so scared sometimes on a kerb; you see people are so tense, it is so basic this chair but so safe, so stable (1-32). The stability and safety of the wheelchair was very important to this user's well-being.

> *I feel a lot more secure, I don't feel like I am going to tip out backwards like I did with the other one, which I did, if I went too steep the wheels at the back wouldn't save me at all, with this one I can get quite low and feel quite happy (8-6).*

In summary improved mobility meant greater independence, comfort, reduced pain, faster more efficient movement, increased safety and stability.

Barriers to mobility

The impact of unreliable equipment, breakdowns and repairs also impacted hugely on independence.

> *... people might not realize the whole mental and emotional well-being becomes impaired as well because you are having to face things (equipment failure) that you shouldn't have to face all the time, to me last week (wheelchair breakdown) 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 and for me I have to get over that ...(4-41).*

The experience of complete occupational disruption is expressed succinctly in this statement from a participant who is unable to self-propel or move themselves independently in a manual wheelchair. *...my life stops…and I can't do anything (4-43).* When equipment has failed participants have become stuck in a range of places: a car, a cinema and a hill to name a few. The following participant expressed enormous frustration at being "stuck" when their wheelchair broke down and also concern at putting their spouse's back at risk of injury when pushing the heavy wheelchair.

> *The last time the controller had completely died I was stuck in my car and my husband had to come to the car park at my work. Well this chair is over 120kg and put me in it and it is over 200kg, you can't push it easily in manual. When someone rings in an emergency*

to get these things fixed it is an emergency and I was stuck in my car and couldn't get out of my car, and I had to go to the bathroom, and in the end my husband had to put me in manual drive and just about put his back out trying to push me into this building to get me in so I could go to the bathroom. It took two hours for someone to finally come and see me and I am sitting in my car and can't go anywhere and I had meetings and stuff, no, it just didn't matter! (4-22).

There was concern expressed about others having to push the power chair if it breaks down because of the significant weight.

You see weight is a huge thing and I don't know why the chairs are so heavy. That is another reason why I picked this one. 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 (7-31).

One participant had to wait at the cinema for alterative transport due to technical problems.

There have been technical problems, one time I was at the movies and I was elevated right up and then it wouldn't come down and so I couldn't fit in the taxi van and I had to get mum to come and get me, because the family van has higher head room (10-32).

The resilience, humour and spirit of adventure helped the next participant to cope with an unexpected breakdown.

I had the "joy" of breaking down the other week; actually it broke down on a hill. That was fun! Luckily I wasn't on my own, I was with a friend. It broke down on the middle of a hill and luckily it was rush hour and there was a whole bunch of workmen going home so we grabbed them and got them to push me up the hill (7-31).

Backup power wheelchairs would be one solution for people who cannot self-propel a backup manual wheelchair, however this is subject to availability as the one participant found:

That is where I think when you have these high tech wheelchairs the backup is not good enough, and the fact that there are no backup power chairs you know. I requested one, but seemingly they [repair service] only have one or two backup wheelchairs available and so seemingly you are third in the queue and the first two people have them. That's the thing you know I have requested when they come to take away the chair to repair it back at the workshop, I have said I need a power chair as a replacement and they turn up and they don't have it with them or it is not available (4-23).

Sometimes people keep or adopt their old power wheelchair as a backup subject to the state of repair and storage: *I've got an old chair in the garage as a backup (8-30),* however that is not everyone's experience: *They didn't let me keep my old power wheelchair; they said it was beyond economic repair and they actually threatened to take my manual wheelchair away if I kept my old power wheelchair (4-42).* Alternatively trying to keep an old power chair going as a backup proved impossible as one participant found:

I tried to keep my old power wheelchair as a backup as in my manual wheelchair I can't move at all and unfortunately I couldn't keep the other one going, so um yeah, I've only got this one and let's hope it keeps rolling on for a wee while (7-39).

On-going maintenance is important but efficient, cost effective provision of upkeep was a concern for one participant:

… the repair company just turns up without an appointment and I am not there, I am at work and they leave a card in my letterbox and it really bugs me that they are wasting tax payers money and I have had years of it with then and when I moved house and I must have rung and told them three times I had moved … quite often they would go to the wrong house and they would say you weren't at home and I would say "I am at work and you do have my work number don't you?"(2-48).

The fear of being stuck was very real for one participant coping alone at home with unreliable equipment. They also did not have access to the use of a reliable backup power wheelchair.

While I was waiting for the repairers to come last week I didn't dare turn of the controller because I thought well if I turn it off it might stop working altogether. I had to carry a phone, well I always carry a cell phone but a normal phone because I thought if I need to go to the bathroom um I might get stuck there, and it is that whole fear, my husband did say to me "look I can come home from work" but I said "look you are half an hour away, why should you have to come home from work" you know I am lucky he has a job that is quite flexible in that respect but…(4-37).

They found being immobile and alone was untenable:

And the repairers go "you have your backup (manual) chair", but I can't self propel myself with it and I don't have anyone to call on and if I do they have to come home from work, and that is not suitable for anyone and I don't think people should have to do that…to go to the bathroom, and things like that becomes very, very difficult. Just to make a cup of tea or whatever, it just becomes really, really difficult! (4-38).

All the multifunction power wheelchairs are currently imported into New Zealand from overseas (Australia, Europe or the United States of America) which can impact on the availability of parts and the effectiveness of repairs as the following participants found.

There is always a wait for parts. I have to say the repair technicians are really good if they have to come out then they will try their best to repair it (multifunction power wheelchair), at least up to a standard where I can use it until the parts come in (from overseas), but I have to say it is on a wing and a prayer (7-33).

I am waiting on the new controller which has to come from overseas, so at the moment I am not feeling particularly independent and it just hammered home to me, what it emphasises is how disabled I am and how reliant on things that I need to work and to work properly, and when you think this chair is expensive and I have had to have it looked at four times in the last two years because there has been some major issues (4-13).

Ready availability of trial and purchased wheelchairs can be affected adversely because the wheelchairs are imported from overseas. This can be frustrating for participants and difficult for suppliers and therapists to manage.

> *It got so bad with the delays, delays, delays and getting the chair that I said to the guy who was the supplier and the therapist that came this day, because I had had phone conversations with both of them : they said yes it will be here in two weeks, and then it still didn't arrive, and then it will be here in another few weeks instead of just saying : "look we don't know when it is going to arrive, you might have to wait three months before this happens"(5-44).*

> *Anyway it got to the stage that when they (the supplier and therapist) came I said before we start I want plain talking, the truth; no more bullshit. If is going to take three weeks, just make sure it is three weeks before you tell me, otherwise that is not providing a service to people (5-46).*

Some participants found there were more technical problems with a multifunction power wheelchair compared to their previous more basic power wheelchairs.

> *…technology wise, I have had more problems in the last two years than my last chair, yeah. I think it is the whole balance of if you need the technology you have to take the downside as well (4-42).*

> *It hasn't been hugely reliable in that it has broken down a lot. The motors haven't been lasting at all, and I don't know what that is or what to do about it (7-32).*

> *I am wearing through the wheels in 4 weeks, every 4 weeks I am having new castors which is not good, very abnormal (7-52).*

> *The swing away leg rest brackets break, this is the third set that has gone in two years…I think they should be made stronger (8-32).*

The kill (cut out) switch at the back is really quite flimsy, it will often cut out, I have had battery issues (10-22).

Theme 2: Environmental Factors Affecting Mobility

People are inseparable from their environments and the contexts in which the multifunction power wheelchairs are used. This was highlighted by comments such as: *The biggest issue is making sure that everywhere I go is accessible (4-72).*

Home

Accessibility within and without the home was essential. The size of the multifunction power wheelchairs meant doorways and passages were too narrow and often had to be widened: *I challenge anyone to call me a bad driver (6-11).* Concern was expressed about damaging walls and doorways: *The size of the chair can be a bit of an issue sometimes scratching the door frame (10-13).* Accessing the home environment was an important criterion for one participant's replacement wheelchair.

I looked into different wheelchairs for ages before I settled on this chair because the other wheelchair I had had for 6 or more years and so obviously it was time to replace it. I had this criteria, it had to be small enough to manoeuvre around the house and a similar size (2-39).

High low (seat elevate) was used to access cupboards so housing modifications were not required. For example accessing the kitchen was essential for one participant who had lost independence in that area.

I cook, um; I can get things in and out of the fridge, in and out of the pantry, um, so yeah, I can do all those things I had to stop doing for 2 to 3 years until I got this (4-49).

One participant found high low or seat elevate invaluable when they were transferring on and off toilets other than their own.

I have been to a friend's place and she has a getting up off the toilet raiser thing and um, I don't like to mess around with someone else's toilet frame so I use my high low to transfer across from that (4-46).

One participant commented that the available funding for modifications is inadequate: *The funding never seems to change, like the building modification's funding that has been the same for the last ten years (2-32).* A change to a wider multifunction power wheelchair has made it difficult for one careful user not to damage their home.

We had to modernize house, trouble with doorways, widened, because with narrow passageways not very good, old manual wheelchair narrower but this power chair only has 2 cm clearance, very bad for knocking walls, wrecks house, old chair had rubber push handles but more marks now from steel castors (6-11).

One user found driving over carpeted floors was not ideal because it increased the roll resistance.

The chair doesn't actually suit the place we are in at the moment, it would be better if we had a house with wooden floors or whatever, it is carpet, but we are moving and that is what I would like to see (1-23).

Accessing the shower without wetting the power chair was a problem for one participant.

The only issue at home is the wet area shower, we don't have a curtain around it we have glass door but we can't shut the shower door so when I transfer out of the chair into the shower I have to try and move it back abit so it doesn't get soaked. I have to shower on half pressure. (4-83).

Another participant also had problems avoiding damage in their home as despite it being recently built it obviously did not include universal design principles.

The power chair was just a bit big to get through the home, it just fitted and I had to be very careful not to scratch the doors or the walls, I think some of the newer homes that are built they don't think about people in wheelchairs (9-22).

One participant found that the single level modern houses were accessible in their neighbourhood because they could drive through the level access internal access garages.

> *Well the only thing for us is that we live in quite a new area and a lot of the houses are quite accessible, one level places and generally, well there are some neighbours down the road and I can get into their houses through their garage so that is fine and this wheelchair goes into their place (2-29).*

However in general many private homes in Auckland are not accessible: *I really need a portable ramp. I can't get into some of my friends' homes and have to sit in their garages (9-28).* The grassy, wet environment common around Auckland homes could also prove challenging as one participant experienced:

> *I got home from work and it started to rain again and I thought I will just get the washing in and I went outside and half the washing was scattered over the backyard and I just momentarily thought I would get it and the minute I went near the grass I thought I shouldn't have done that and I tried to back up and the thing was stuck and then it started to rain and it was three o clock and I was out there and I didn't have a phone, the children would have been coming home from school but the doors were all locked …but I managed to get the wheelchair to go forward and then I managed to get free but there was mud all over the chair and the tyres and I had to traipse it all through the house (2-11).*

School and Work

Workplaces can be more accessible for a multifunction power wheelchair user, not only from a physical perspective but also visually and socially such as when a person can stand.

> *When I first got the wheelchair and stood up and I said "wow, this is a completely different perspective that you see the office from" because where I worked previously the office had cubicles and of course everyone else could see over the cubicles to see who was there but I use to have to do a full journey around the office to see who was in and who*

was out and if I was looking for someone I could be traipsing around the entire office whereas once I got this chair I could stand-up and I suddenly knew how everyone else knew how such and such was in, because they could see over, and it is the little things like that you often forget (7-7).

High-low function assisted this user with accessing shelves at work.

I actually work at a little local place so it is actually fine there because I can reach stuff and do things quite easily so it certainly has made life a lot easier that way and , um, and yeah, I need to use tilt to get in and out (4-56).

The greater battery capacity of a multifunction power wheelchair was an advantage for local work related trips for this user.

Probably for work it has made a significant difference because part of my job I have to go down to the bank almost on a daily basis and then there are other shops that are a bit further a field and the other wheelchair would be very touch and go to go that distance on the batteries (2-9).

The weight of the multifunction power wheelchairs could also be a barrier to accessibility at school and work as one busy mother found in dramatic circumstances.

The other problem I have had connected to the weight is that 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 ... The first time was really horrendous because it is a glass elevator and my children had hopped in with me and see that would have possibly tipped it over the weight limit, they are a couple of lightweights but they would probably be another 50kgs together so we get into this elevator and we are all jammed in and basically it wouldn't go to the top, and so the door wouldn't open and it blew something and it wouldn't go up or down and there was all these people peering in at us and it was a Friday afternoon and they tried ringing the lift company and they weren't very helpful

and so one of the teachers said "OK let's just ring the fire brigade"... anyway the fire brigade has a key that they turn to release the lift...

The second time it happened I was reluctant to give the lift a go but it was raining and everyone reassured me it would be fine so I gave it a go because otherwise I have to go all the way around and I would get soaking wet to avoid using this lift … and I got stuck again, and so the fire brigade came out again, and I haven't used it since, and two weeks ago I was at a training session in town, and they have a water powered lift there, and I came down in that lift and on this occasion it had gone down too far, and the door wouldn't open because it had blown a valve, and I was stuck in that,... so the weight thing is a really huge issue ... and that is why all these things are happening, and you know these lifts in buildings can't take the weight. I am starting to get lift paranoia now that I never had before; horrible... you know it is not on (2-44).

Work was a very important part of life for some participants that they did not want to compromise with unreliable equipment:

…I live a normal life as I possibly can when things go wrong [wheelchair breakdown] everything is disrupted and I am lucky that I work in a place with a flexible work environment and the people I work with are understanding but you know something goes wrong and it is beyond my control and I shouldn't have to do that (4-33).

Outdoor Being and Doing

Outdoor environments were accessed for enjoyment and fulfilment of roles such as parent and grandparent were mentioned:

The chair has been really good, we have young children and they are very sporty and athletic and like to be outside doing things and with this chair we can do a lot more around the neighbourhood where we live and getting to their school is down a steep pathway, and this chair handles it with ease whereas the other chair was touch and go and if it was raining I would be nervous about it, as it didn't have all its wheels on the ground,… the only negative is the weight and if you get off the path and onto a bit of grass you have to be careful as you can easily get stuck (2-3).

> *I go outside and next door to visit my grandchildren. For instance they have just got this tent and I can go out there with them and their pets, and get out and see what they are talking about (3-11).*

The role of friend was also enhanced. Being able to stand up at a concert with friends who are also standing was a memorable experience. Being able to stand enabled full participation and an improved viewing height to see. *... I went to a concert in a field and normally I would've missed out on half the concert because I was too low down but because I could stand-up I could see (7-20).* In contrast one participant enjoyed the solitude of being in their home garden however being stuck outside unable to move in cold temperatures was a serious health and safety risk.

> *Very useful machine but downside is trouble with suspension, OK with concrete, but grass especially wet grass, it slips, many times I have got stuck, very heavy to move, 140kg, but in the winter I can't go near the grass I am stuck all the time, one time, carer away, so no one around for a long time stuck in the cold, I always have phone now outside (6-10).*

Use of a mobile phone as mentioned above and next can improve safety and confidence in the outdoors as help could be summoned. *...one day I had a puncture when I was down the street but I always take my mobile phone with me so I can ring… (5-51).*

Other recreational activities were also mentioned such as shooting: *When I was learning to shoot the power chair assisted with that, leaning back and tilting back so you can balance the gun properly (10-6)*; accessing the park: *... go for lots of "walks" in the park (1-20)* and shopping: *I go to the local mall if I need to, 4km away, I haven't been funded a vehicle yet (10-4).* Access into and around shops was a common problem: *I went to a shop that was not wheelchair friendly even though they told me it was wheelchair friendly (9-27).* High low was useful for accessing high counters however smaller corner shops (called "dairies" in New Zealand) can often be inaccessible and the public's understanding of accessibility limited as demonstrated in the following comment:

> *I use the high low to get up to shop counters and that is because most of them are pretty high, um, round some shops especially smaller dairies I have had a lot of trouble getting*

in them mainly because the stores are so packed with stuff you can't get down the aisles to turn around, other shops are OK but I have come across some that when you ring up they say they are accessible and then when you get there you can't get into them (9-16).

Spectator sports are a big part of New Zealand life for some people:

The chair has been really good, it has got me out and about, um, I like sports and I normally go and watch league every Saturday in it when it is on, and if I didn't have the chair I wouldn't be able to because I wouldn't be able to get there (9-4).

One participant needs their multifunction power wheelchair to watch live sports although they can get stuck.

I wouldn't mind it handling better on softer grass; it is very heavy; if it has been raining or the ground is soft you can get stuck quite often. It has happened to me a few times at sports grounds (9-10).

Bush walks were able to be accessed in a multifunction power wheelchair.

There are some of these bush walks, we can go through this gully and right around the village, and there are lots of walking tracks and things and we have got to make the most of those (2-6).

Footpaths could be challenging as one user described. This was confirmed by observations of the local footpaths around some of the participants' homes which were often less than ideal.

Some of the roads and footpaths were diabolical with potholes and sometimes no ramping down to the road so I would have to use driveways to cross the road. I think with the two wheels that have air in them (centre wheels on mid wheel drive) they are a little bit hard suspension wise on the bumps just a little bit bumpy, the footpaths camber out to the road and that is a bit scary because you feel like you can tip over (9-19).

The attitudes of the other people sharing a footpath were perceived as a social barrier but it also an environmental barrier because of the small footpaths.

> *A lot of people will not get out of your way they just expect you to stop, they expect you to get out of the way and manoeuvre around them which sometimes is abit of a pain especially if you are on a small footpath and you can't get out of their way, they are on the footpath and they want you to get out of the way (9-20).*

Managing slopes was observed to be an issue by one user and they felt a stable four wheeled drive power chair needed to be considered for more users.

> *I have worked with people with disabilities and they are so scared of a power chair and a little bit of a slope. You can see people are frightened and tense up. This chair is so stable and sits lovely and I think it is a chair that should be looked at for more people (1-3).*

Durability of batteries and managing hills was mentioned: *Hilly places don't take any effort, the batteries last a whole day (10-34); I may need more powerful motors because I have noticed when I go up an incline it really makes hard work on the motors. The distance it goes is great, I have gone 20 to 30 kilometres (9-25).*

Soft terrain has to be avoided because of the risk of becoming stuck. *It won't go over loose sand, but it can go over very rough ground. As I live on a rural coastal property I can get to the road and go down the road (3-5), Sand and loose gravel I avoid (10-34).*

> *I can do all those things and not worry too much about the steep footpath or if it has been raining. There is this nice mossy cover on this pavement and the other wheelchair would slew sideways as it went up the hill as it was slippery and it would lose traction (2-22).*

Unfortunately not all the multifunction power wheelchairs handled hills and wet surfaces safely.

> *The chair is quite bad in that it will slide quite often, for example down a hill and then it's not controllable, even when it is not raining it will just slide, other than that it is a good*

chair but I am a careful driver, if it was someone less careful there would be a lot of accidents if you know what I mean (7-51).

One participant has always made a point of asking about wheelchair accessibility.

… it is a bigger chair than my other one, but I can't say I have many problems really, compared with my old wheelchair, it is a bit wider and a bit bigger but I've always spent my life asking people if they are wheelchair accessible, I mean that hasn't changed (4-72).

The same user found their mid-wheel drive multifunction power wheelchairs can get stuck on door steps/thresholds.

The chair is actually pretty zippy and it is actually me just retraining myself to use the ramp/curb function on it and there is times when there is a bit of a lip, more than a couple of inches and it can be difficult even with the ramp/curb thing it can get stuck and my partner gives it a bit of a wriggle and jiggle or pulls on it. There is some trade-off with mid-wheel drive, it doesn't happen too often, sometimes I look at a shop or something and decide not to go in because I don't want to get stuck or something and when it does it could career all over the place and it could break a window. I did it on the weekend it was a two inch aluminium lip but fortunately my husband was with me (4-80).

Ground clearance was also an issue for another participant: *The only thing I think with this and other chairs is the ground clearance, right underneath, there is not enough clearance there I don't think (1-14).*

Another user found reduced suspension in their new wheelchair impacted how they could drive over bumps.

I am careful in the way I drive it because the other wheelchair had a suspension system and I was able to hit bumps at a different angle in order to get up them. I had to hit them at a certain angle, which in this chair if I did the same; I would probably tip (7-50).

Additionally when outdoors weather is another consideration, it can be a challenge because it is hard for wheelchair users to keep themselves, their wheelchair and their controls dry.

> *I never go out when it is wet because if you get wet or you get the controls wet you are in trouble and I have wet weather gear I can put on but now I have to have someone with me when I wear that (5-32).*

Good weather was able to be enjoyed: *The chair is quite good for sunbathing (10-30).*
Some participants mentioned they only used their power wheelchair for outdoor use: *I use the chair to access the community when it is too far to go in my manual wheelchair (10-7).*

In summary the participants voiced many benefits such as improved ability to access the outdoors for many occupations, increased distance and durability however there were still considerations they had to take into account such as the risk of becoming stuck, inaccessibility into shops, soft terrain and wet weather. The ability to use a mobile phone improved safety because help could be summoned however urban design impacted on participants' level of participation.

Transport Issues

Transport was a huge issue for all participants whether it was personal or public. Some participants had access to more funding, personal or otherwise and had self-drive vehicles.

> *... I drive, I have a vehicle with a hoist, I get out of the chair and drive from the driver's seat, I go through the back door, it is a Land Rover Discovery, the door opens automatically and then I get out and in and I lift up on the hoist and swing it in and then I climb up onto the driver's front seat (1-22).*

Personal transport for multifunction power wheelchair users involves purchasing a vehicle that has a ramp or a hoist or vehicle modifications and this can be prohibitively expensive.

> *I wish I did (drive from my power wheelchair), but it is a bit expensive to get a car modified, so no, I don't drive from it, but I have a hoist in a van…We had to modify the van when we got this chair, a wider hoist and also I had to have the flooring redone because of the weight (7-30).*

... we had to go out and spend a lot of money on a vehicle so we could transport it because my old chair was lightweight enough that it could go on a little hoist on the back of my car, and I could push it in and walk around the car, and really that chair was just for distances and doing things outside the house, then four years ago I had to start using it inside, because I just stopped walking, I broke my ankle for the third time and I just didn't recover (4-61).

The process of transferring oneself and loading the wheelchair could be time consuming and complicated as described by the following participants:

High-low raiser useful for getting to car (car transfers), and wife puts wheelchair into boot, we had many difficulties getting wheelchair into car because ramp is not very easy, hard to reach, I made up a little ramp with a clamp and then it is OK with no slipping because no bolt(on ramp)...probably thirty minutes to get ready to go out and then to come back another 30 minutes so big exercise, no good just to pop out, big job (6-5).

We have been fiddling with the back of the wheelchair because we are going away in a couple of weeks and we thought we would try and get it into the back of the car because we have never tried it before and then obviously when we put it back it was not as upright as this (2-19).

The above is in contrast to having a van with hoist which required less effort and time:

I have my own van, you just drive straight up onto the hoist and the into the back of the wagon, carer straps my chair down and puts my seatbelt on, I have a chest strap to hold me stable which helps (9-21).

The weight of the power wheelchair was an issue for transporting.

I only recently found out it weighs 186 kg and I was originally told it weighed 140 kg so that creates a lot of problems with transporting it, and it's probably too heavy to fit on

the hoist at the moment on my vehicle so that is probably the thing I don't feel happy about is the weight (2-2).

Staying at home or using the old wheelchair because of transport issues was less than ideal and it was important a convenient mode of transportation was available that matched the user and their wheelchair .

Yes, we still have the old wheelchair and we still use that when we go to places, we use the old hoist, ramps and the old wheelchair so that is really awkward because I would rather take this [new wheelchair] but I can't because I have no way to transport it (2-37).

Now I have my car, I probably spend my time getting out and about more, I have had a vehicle 6 months less than the chair because I had to wait to get the chair so for about 6 months my life stopped because the chair and car didn't do what I wanted them to do, just because my needs had changed and my disabilities had changed and um, yeah, that was quite hard but once I got it all up and running it was great (4-74).

Vehicle adaptation failure could also be another issue to deal with: *I have a car with a side ramp that comes out and my ramp and door wouldn't work last week so got stuck in the car park at work (4-13).*

Only one participant used public transport whereas some of the other participants lived in areas where it was not as convenient or readily available.

I wouldn't manage without the power chair, my life would be hell without it, um, when I go out I can get it into a small space, this chair can be made smaller in length than any other chair you know. It turns on a penny, I can fit on a bus or a train which suits me fine and those people have become more and more helpful as time has gone on ...When the weather is good and um I can go up to the doctor and I can go up to the shopping centre, I can get on the bus and go down to other shops and so getting on and off a bus is really good (5-19).

Participants found the availability and cost of taxis curtailed trips into the community even for essential appointments.

> *It is very difficult to get reliable taxi and they have school rounds and if you have doctor's appointment at 9am, spouse has to help, expensive to use mobility taxis, limited subsidies and not reliable so prefer home vehicle (6-5).*

> *I don't go swimming anymore because the taxi fares have gone up and I can only afford one outing in my power chair a week. I use to go out a lot more when I could get into the ordinary taxi with the folding wheelchair because it was cheaper! (3-10).*

> *I use bus and train as much as possible and if that is not possible I will use the mobility taxis but it is so expensive now I avoid going anywhere that I have to use that sort of transport … I mean even if I needed to go to a hospital appointment I would be looking at if I could get close enough to my destination by public transport off a bus (5-34).*

> *I usually transport the power chair in a taxi van with a hoist in the back. Travelling in the power chair can be quite uncomfortable compared to a car seat, and it is very heavy, which is a bit of a down side (10-11).*

Transporting a heavy multifunction power wheelchair on a provincial plane was challenging because of the weight.

> *I went to see a friend in another city and in the end I had to take my manual wheelchair because they couldn't take a chair of this weight on the plane, because the doors on the smaller planes are not big enough to provincial centres, so I took my manual wheelchair down with me and I ended up hiring a power chair down there, so my friend did not have to push me around all the time and also if I hadn't taken the manual wheelchair down my friend would not have been able to pick me up from the airport and we wouldn't have been able to do a couple of day trips when we were down there (4-65).*

Hiring a power wheelchair in another city is not always an option because people lose their individual seating, which they need for postural comfort and support, as one participant explained.

> *I am booked on a direct flight and I haven't phoned the airline about my power wheelchair, I am worried about hiring one and then I will lose all my seating, it is not easily transferable (4-89).*

The weight and size of the multifunction power wheelchair could make it impractical for overseas travel. The impact of limited mobility and dependence on a power wheelchair can limit people's future plans.

> *When you come to travel it becomes another issue and I know we want to look at going overseas in a couple of years' time and logistically it is not going to happen with this chair and I just need to be realistic that I will need to hire a collapsible power chair either over there or over here and take my manual wheelchair which then means I am totally dependent on my partner for everything (4-66).*

In summary affordable convenient transport was an issue for some of the participants and it limited their participation outside of the home. Only one of the ten participants interviewed used public transport and two had independently driven vehicles funded by ACC. The weight of the multifunction power wheelchairs could be a problem requiring reinforcing of vehicle floors and prohibited taking them on smaller provincial planes. The issue of portability plus the lack of collapsibility could also make use for overseas travel impractical.

Theme 3: Benefits of Power Functions

General benefits of functions

Multifunction power wheelchairs were defined for the purposes of the research as having more than one power function so all the participants had at least two power functions on their power wheelchair (as shown in Table 1). Although designers incorporate a number of features into power wheelchairs, the participants provided more insight into the way they used these features. Many general benefits were expressed by the participants in relation to power function use such

as independence discussed in the previous section, their individual requirements and backgrounds impacted on their choice of mobility base and functions as demonstrated in the following quote:

> *…4 x 4 chair [multifunction power wheelchair] goes up, down, reclines, tilts, lights…visibility is not so good at night when I go out so it is good to have the lights…I knew what I wanted because I come from a mechanical background, before my accident I worked with farming and machines so I understand all that a lot more than other people probably and I just wanted something stable that would allow me to go off the road a bit more (1-9).*

This user was very clear about their power wheelchair requirements:

> *It (chair) had to be mid-wheel drive and high enough for me to get off, it needed to be light enough to go on the hoist and …anyway I looked at lots of chairs and they were either too big like the other company's one, this chair wasn't such a monster, it was so huge and so long and the high low didn't go high enough so I couldn't get off it because I am quite tall and if my legs are straight I can't get off it … (2-40).*

This user really appreciated having all their power functions (tilt and high low) in conjunction with comfortable seating.

> *It is brilliant, it is my legs, it suits all my purposes, it tilts backwards and forwards, um, it lifts up quite high so if I need to get into a high cupboard I can, everything is comfortable on it, the back, the headrest (9-3).*

Ease of use, increased comfort, increased pressure relief and reduced pain were also mentioned by participants.

> *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 (9-24).*

There were also many comments about improved social interaction and better proximity to see and hear and as one person succinctly expressed it…*interacting with people is huge! (4-75)* and more examples of social independence will discussed under the following theme of independence

Tilt function

Tilt function was by all 10 participants for many reasons: to manage pain, to move, to pressure relieve, to weight shift, to relax, to rest, to maintain an upright position on a hill, to stretch and to aid an upright head position.

> *I use the tilt constantly, the seat tilt, I use them all constantly many times a day to function, I can lower it down, I can tilt myself forward at the table, I can't even put a piece of paper on the table now, I've got to manoeuvre it on my knee, but you can function as long as you can work out a way (5-37).*

Sometimes tilt was just used to move:

> *I use tilt in space the most because I am use to that; I've used it for years' it depends how I feel, sometimes I just tilt back or move myself I don't always know why I do it but I'll just move myself (8-21).*

Being able to change position frequently because of back pain was important to one participant.

> *... because I have trouble with back pain and I can only sit in one position for short time so I have to change back and tilt because when working on computer OK but can't sit for long time, yes, tilt and recline mostly used (6-13).*

One participant used tilt regularly for pressure relief: *For pressure management, I honestly try to use the tilt; every half an hour for at least 10 to 15 minutes (9-13).* Another participant liked to relax in a tilted position: *Use tilt for relaxing sometimes (10-5).* It is also very important to use tilt on slopes to shift the centre of gravity backwards or else a fall forward out of the wheelchair can result: *... probably use the chair tilt the most, to lean back on a hill (10-17),* or tippiness as the next participant found. *Once I went down a steep driveway and forgot to tilt back and nearly*

tipped out but that was driver error (9-26). Falls from wheelchairs can result in injury as reported below:

> *The high low is the one I use the most, the tilt I haven't, but I have been told I need to use it more, particularly when I am out and about because I am finding that um when I go down a ramp it is tilting forward, I need to put it into tilt and recline to keep the weight at the back, as it actually propelled me out about a month ago and I actually fell forward out of the chair and smacked my face on the concrete, so at the moment me and my chair are not on very good terms between that and what happened last week (4-9).*

Tilt also provides a gravitational weight shift to help with positioning: *I got a tilting one [multifunction power wheelchair] to stop my head flopping around and to try and save my neck, I use to use a neck brace, a soft one (5- 8).* Finally tilt is used for comfort.

> *I use the tilt function because obviously I am just sitting and my skin gets itchy actually and the whole sitting down is not very good for you, so I use the tilt function because I never really get out of my chair (2-17).*

Recline function

Recline function was used by 7 out of the 10 participants for many reasons such as to stretch: and to relieve back pain:

> *Recline is so good because it allows me to stretch because I am sat all the time. Recline is lovely it lets you stretch out. I can do that during the day at my job, at my desk or where ever (1-11)…The recliner is the one I use a lot, I use that every day, a couple of times a day, if my back is a bit uncomfortable I just recline and have abit of a stretch (1-26).*

Recline was also used to relax: *I use the recline [function] to relax (10-18),* to weight shift, to pressure relieve: *I use the power recline all the time to take the pressure off my lower back and bottom and legs, it is really good (9-3)…*, and for independently accessing services such as going to the beauty therapist, doctor, hairdressers or dentist.

> *..the recline has also helped my independence for example, um, whenever I went to the hairdressers I had to be transferred out of my chair when they washed it but now I can just recline to the basin and they can wash my hair so now I can go to the hairdressers all by myself (7-15)…All those little things like eyebrows being plucked, I just recline and have someone do that rather than transfer out, also for medical things because sometimes I need my ears checked and things like that, I can just do the recline and I don't have to transfer out (7-18).*

One participant was able to power nap to manage fatigue.

> *Sometimes I need to recline to relieve pressure and pain and I can do 15 to 20 minutes like that in total relaxation and that can revive me. It has been essential to be able to lie back- none one day and maybe 2 to 3 times the next day (5-29).*

One participant used power recline to assist being dressed in the wheelchair:

> *…one of my carers she lifts me and puts my skirt over my head and down and I lie back and she lifts my legs and pulls my skirt down, …so I use recline every morning for dressing [demonstration] (5-49).*

Recline was used in conjunction with standing for stability.

> *I think I use recline quite a bit for just shifting you know the way I am sitting so I am in a different position, um, also when I am standing up to recline back so I feel a bit more safe in standing (7-14).*

Seat high low function

High low was used by 6 out of the 10 participants and was mentioned as helping with many daily occupations and activities, for example to assist with transfers, accessing cupboards, shelves: *Elevate-high-low useful… just for up to cupboards and transfers (6-13); in the shops it is great because I can reach things on most shelves, the same at the library I can do all that (4-50);* washing: *I wouldn't be able to function without high low very much at all, just basic things, I wouldn't be able to get the washing out of the washing machine without high-low (2-43);*

cooking, switches, shopping: *High low helps to access light switches, shelves in shops and all that sort of stuff (10-19);* communicating and seeing:

> *If I am right at the back of the church and there's a big fella in front of me or I can't see the words sometimes I go straight up. At the RSA (Returned Servicemen's Association), um, 7pm, we all have to stand for the prayer "Lest We Forget" (8-17).*

A high-low assisted stand was essential for one participant's independent function in daily life.

> *Well the high low function means I can get up and stand-up because I can still do standing and self transfers to go to the toilet, get into bed, stand at the kitchen bench, ah, I couldn't stand-up if I didn't have high low, it has always been critical, it has been really critical with the condition that I have got and I am at the point that I need to do the standing up thing a bit more so high-low is an important part of that (2-13).*

High-low assisted different styles of transfers, from standing to transfer boards.

> *To transfer I do the high low as high as it will go and then I do the anterior tilt and sort of slide out of it…then I motor it back down again so I can get back into it (2-15).*

> *Sometimes I use high low and sometimes not, because it is the perfect seat height for me to transfer out of anyway it is usually OK, I transfer off my Lazyboy [electric armchair] chair, I transfer off my bed, I transfer off my toilet so it is actually really good for that (4-46).*

> *…no knees, legs strength ,now I have to transfer on a transferring board…High-low assists with transfers; I have the hospital bed at the right height for transferring bed to chair and also the commode chair for in the shower… high-low raiser useful for getting to car [car transfers] (6-5).*

Most importantly high-low was mentioned as helping socially to communicate face to face, to compensate for having hearing loss, dysphasia or a soft voice and generally to have a closer more appropriate position relative to others.

The chair is a positive socially because when I go out I can talk to people without them having to shout. When I go to a gathering I tend to position myself halfway between down and up so I'm not too far from someone sitting next to me or someone standing near me who wants to talk and it a lot more comfortable like that, especially for me. With my soft voice if it is a long night it starts to wear out (8-8).

Participants reported many benefits from the use of high- low however this is in direct contrast to the experience of one participant without high-low seat function:

They [assessing therapists] didn't think high low would be useful for me but I think it would especially when you go out in a social situation and you are staring at everyone's backsides which is where you are you know, and I avoid crowds for that reason because you are just down here and everyone else is up there and they are all talking away and you can't hear what they say and they don't want to be bothered to come down and talk to you whereas if I had the lifting chair I could have participated in a lot of those things over the year but the powers that be wouldn't justify that (5-24).

One participant's observation of other wheelchair users supports the above statement: *I think with people that are non-vocal and non-verbal the high –low is really good because otherwise people tend to speak across them or over them (1-27).*

Elevating leg rest function

Elevating leg rests were used by 3 out of the 10 participants and were reported as assisting with the management of physical symptoms such as helping manage oedema: *The elevating leg rests are good for draining the fluid away from the feet, when they get swollen (10-20);* swelling, to pressure relieve, and to manage pain: *Lifting my legs up makes a big difference [to my pain] so I get up abit more in my chair (8-4).* For participants that needed elevating leg rests they were used on a daily basis as explained in the following statement:

I use the elevating leg rests every day, they have a bearing on how the drainage is going, before the mornings out I'll have my legs up, I went to the mall with my granddaughter

and we shopped and I had my legs in one position pretty much because of going in and around and as soon as I come inside the door I'll have my feet up. It depends how my bum feels, if it is feeling pressured I'll have the legs right up like this [demonstrates] because it takes all the pressure off my backside and sometimes I can recline but it does change the position of my bottom on the chair and it pushes the cushion forward (5-48).

Standing function

Standing to interact in a power wheelchair was seen as a huge benefit in comparison to being stuck in a standing frame or in a permanently low seated position. This is because the person can move themselves around in their environment and not be isolated from other people or activities or occupations they want to engage in as explained in the following statement: *I can do my standing frame exercises in the pub if I want or at a concert, I don't have to be at home bored (7-57).* Standing improved comfort, circulation and enabled stretching. Standing also gave increased independence in many areas such as banking, printing and faxing as described by one participant:

It is really cool just being able to rock up to the bank and stand-up and have a proper conversation with the teller, and see them count out the money and being able to print and fax things in the office (7-26).

Solid knee blocks gave more support in standing for the participant user than fabric knee blocks. *It has quite a secure thing for the standing [solid knee blocks] and the others just have a material thing across the front [fabric knee blocks] (7-3).* They also reported they were able to stand more frequently:

…I use stand quite a lot , 5 to 10 times, depends how often, sometimes I use it to stand-up to press a button and then sit down, other times I might actually decide to stand-up for half an hour to have a decent conversation with somebody (7-43).

They used the standing function for reasonable periods of time and the need for a standing frame was negated with the provision of a standing power wheelchair. The freedom to be able to move around in standing is an advantage for social participation.

...standing was mentioned and I said I can stand, I can do standing transfers, and the therapist said why don't you get a chair you can try standing transfers in and I'd always done standing in a standing frame and you see you'd always have to have the time to transfer out and stand in the standing frame for a certain amount of time whereas with this chair I don't need a standing frame now…I don't really need the standing frame because I've got this chair to stand me up and do that and the great thing about this is that you know I am not stuck in a standing frame or whatever and not able to move. I'm actually able to move around while standing which is cool and I'm not sure other chairs can do that. ... (7-56).

The wheelchair seating for a standing wheelchair needs to be comfortable in a range of positions from sitting to standing as the following statement explains:

Finding seating that supported me and did all the pressure relief thing and was also comfortable in sitting as well as standing, because I do stand for quite abit of the time as well, I needed the seating to mould to both, where the pressure goes is completely different as well so we did take quite a while to get the right seating, ended up with a custom [handmade foam] cushion with an air insert in the back (7-48).

This participant felt it would have been advantageous to have had a power wheelchair with power stand when they were younger because it would have enabled more frequent standing with all the associated benefits.

And for me I think if I had had the chair when I was younger that would've made a huge difference as well because um, we all know what we are like when we are teenagers, we argue with our parents about when why we need to do standing frame time and why we need to do other things, whereas if I could've stood up at any old time I would've have been quote happy to do it, so from a therapeutic aspect I think people should look at it a bit more at all ages but specifically teenagers (7-57).

One participant was not aware standing was a possibility and felt that it could assist with managing their chronic back pain:

I'd love a stand-up wheelchair but I wouldn't have thought it would be funded (8-34).

Combined functions

One participant used a combination of power functions all the time to maintain seated position and alleviate pain and discomfort.

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 (5-42).

This participant uses three functions frequently especially elevating leg rests.

It is awesome I can recline, tilt back and lift the footplates up a bit and have a good afternoon snooze in it (9-14)…I use the tilt, recline, and the leg elevate the most, when you go down the footpath, ramp, shop thresholds you have to have the legs high-up. I also use leg elevate to change leg positions and manage the swelling. The leg elevate makes a big difference (9-23).

Whereas another participant did not want too many power functions and appreciated ease of use.

…some of the chairs I tried had too many functions for me and I'm a girl and I got a bit lost on all the functions. I never forget I was trialling one and I was trying to stand-up and there was just way too many buttons and I didn't know how to get back down again so that is why I chose this chair because it has less functions but it stands up and reclines (7-2).

The ability to use combinations of two or more power functions enhanced users' comfort, reduced pain, the ability to rest, manage oedema, mobilise and stand up.

Theme 4: Importance of independence

Increased independence

There were many comments from every participant about a general increase in independence in their everyday lives. Without exception the mutifunctionality of the wheelchairs was used to increase their ability to independently carry out a range of tasks inherent in their life roles. *You can't put a price on independence. Independence is huge! (4-90).* It was one area that participants were very enthusiastic and positive about in terms of mobility, functional gains and energy conservation. This participant had regained lost independence as 'voiced' below:

> *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. It just used up so much energy and I can do things in half the time I use to do before, I can do more in the chair (multifunction power wheelchair) and I am more independent now than I probably ever have been in the last ten years (4-57).*

Participants' requirements for independent function were very individual to them. Underlying this was the fact that the ability to change their body position with the use of the power functions increased their overall well-being and comfort. This subsequently extended the length of time they could be in the wheelchair and hence be effectively engaged in their lives. *I wouldn't manage without my power chair. It is so necessary. I wouldn't be able to live so independently without it (3-7).*

The multifunction power wheelchair enabled participants to do so many things both in and out of the home environment. It gave them increased choice and confidence. *Before this chair I always made sure someone was around, that I knew the environment well enough so I could cope in it, whereas now I can cope, which has given me that bit of independence (7-6).*

Participants reported they used their multifunction power wheelchairs for long periods of time. *I use the chair from the minute I get out of bed until I go to bed, I do transfer out of it (4-45).* Most participants are in the wheelchair all day. *Basically I am in it 100 percent of the time, I basically don't walk anymore, and this is my transport (2-70).* The power wheelchair provided access to

engagement in the occupations of living. Participants expressed many very specific examples of increased independence through the use of the multifunction power wheelchair such as: to access kitchen, bar, clothesline; to get outside; to dress; to transfer; to converse, chat; to access the garden; to access the vehicle; to switch on the light; to open doors, to operate lifts; to go to the bank and see the teller; to use a printer and fax; to put on makeup; to go to the dentist, hairdresser; and to change position.

> *When I am at home, I would mostly have it raised up, and I have had the inhibitors [lockout on the driving when in elevated seat position] removed so I am moving about raised up, it helps because of my very weak arms to get things out of the dishwasher, or the drawer, or do something at the sink or bench, or whatever… (2-25).*

Getting to the toilet on time is essential. *I use the chair to get to the toilet. I need to get to the toilet quickly. That's something that happens with MS [multiple sclerosis] (3-8).* Using the computer and the phone was achieved by using the power tilt function to gravity assist a weak arm into position.

> *There is no muscle tone in my arm to lift it, I can't lift it, to get this arm over towards the keyboard I lift it if I can, I use the tilt of my chair, tilt is the difference between being able to move and not move. If I tilt to the right position I can get my arm to the edge of the table and it takes some pressure off and it can sit on the table and then my finger go numb, but that is alright because I can use tilt to move my arm again, it means I can use the computer and the phone (5-23).*

Standing was also used to enable reach and function with weak arms.

> *It has been really amazing for me because I have limited reach and everything like that because I am quite weak, and so with this chair I can stand-up and get into a better position to do things such as switch on a light, and open doors, and just do little things like that, which has increased my confidence as well, because I know I can cope in certain environments, such as pressing lift buttons, and things like that so I am more likely to go out by myself (7-5).*

Being able to cook and prepare meals was very important to this participant enabling a practical contribution to home life and reducing the burden of domestic tasks for their spouse. *It was the whole justification, as my spouse was having to come home from work, and cook, because I couldn't reach anything, but now with the high low I can (4-63).* Power recline was used by one participant to position and support herself while she was dressed. *I get dressed in the chair (5-21).* Additional, more recently available features such as an environmental control function also gave independence with leisure and work. *In terms of the infrared controls it's great, changing channels and stereo music, having teething problems at the moment but it can do a lot more, [computer] mouse control and that sort of stuff (8-9).*

Social independence

The ability to interact independently was highly valued. One participant who was dysphasic found the ability to physically rise to eye level was a very important aid to communication: *High low important because stroke makes it very difficult to make conversation and to converse in party mode and concentrate on words; so doubly important as doubly hard (6-8).* Another participant had a hearing impediment:

> *…even when you are going out and lots of people are standing and milling around and having conversations and I can actually bring myself up to eye level which is great…because I have a slight hearing impairment and when I am in crowds and lots of people are talking I actually have to be quite close to someone to hear and I will actually watch what they are saying as well so I can follow the whole conversation… it is just one of those things and it does make a difference, I like to be at eye level with people (4-54).*

Independence was gained in different social situations through the use of power stand function such as at the bank:

> *...it is really cool just being able to rock up to the bank and stand-up and have a proper conversation with the teller, and see them count out the money and being able to print and fax things in the office (7-6).*

Standing in a bar*:*

> *The social aspect of being able to stand at a bar which is quite a normal thing for people to do but it meant a lot to me to be able to go to a bar and order my own drinks, stand there and chat to people (7-7).*

Using seat high low to reach a restaurant bar:

> *I remember going to a restaurant recently and there were only bar stools around a table left and my friend looked at me, "how are you going to reach a table to eat a meal? And I said "hang on a minute" and I put my chair up high and it worked really well (4-50).*

Also mentioned was the freedom to go shopping:

> *I would go to the local shopping centre and sit and watch people go by, and chat to people I knew, and do abit of shopping, and have a look in the shops…just to be able to do what I wanted to do, go and visit friends (9-8).*

Visiting local friends, new and old was important to one participant who no longer worked: *I use the chair to visit a lot of people and have a chat and a coffee, every day, old family and friends and new acquaintances (9-17).*

In summary being able to independently and effectively socially interact was highly valued and meaningful to participants.

Barriers to independence

Although all the participants discussed the positive changes in their lives as a result of having a multifunction power wheelchair, they also identified barriers that occurred. There were also some aspects where assistance was required for some participants who were weaker such as charging batteries: *People plug it in and charge it for me (7-27),* and moving the wheelchair away from the bed or shower.

My spouse does the charging, we put the chair in our walk in wardrobe, it is quite a quiet charger so it is not a problem, but it is quite nice not to have it right there, if my husband is away I have to plug it in right next to the bed, that's not a big deal(4-78)

I can't move the chair away from the shower; I put a towel on the seat because the water splashes around. When my husband is home on the weekends he can move the chair right out of the way so I can have a proper shower, the shower is something I don't want to change at the moment, it will be costly (4-84).

The huge weight of multifunction power wheelchairs was also mentioned as a barrier to independence as it meant people had to be even more careful in soft terrains. This is also an environmental factor as highlighted in the theme of that name.

I have to be cautious I don't end up stuck somewhere. I think it is basically related to the weight of this chair (multifunction power wheelchairs can weigh up to 160 kg) because the previous chair only weighed 80 kg (2-8).

Limited funding was also expressed as a barrier to independence because it limited choices and options for power wheelchairs and vehicles. The constrained funding impacted on this participant at many levels as described in the following passage:

The whole thing with driving a vehicle here to work with my old power chair was I couldn't totally transfer in and out by myself and someone from the office downstairs would have to help me…I know what happened, I fell over in the car park. I had this sort of month of all these things that went wrong, falling over in the car park was the last straw that broke the camel's back and I decided I would take the taxi option which meant I could bring this [heavier, multifunction power] wheelchair….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!… I mean how they [the funders] think that the current funding helps, that doesn't even put a hoist into a van, so unrealistic (2-32).

The above comment also showed how many challenges a person may have to deal with including limited funding. The next comment expressed the need to "fight" for a specific function on their multifunction power wheelchair.

> *I had to fight to get the high low. I had to justify why I need the high-low and it is just like, I wouldn't ask for it if I didn't need it, I wouldn't want all the bells and whistles so I actually said I don't need tilt and recline but it is actually just as well I got the tilt (4-60).*

Another participant concurred with the previous comment and felt that the therapist had to strongly advocate for them to have the multifunction power wheelchair.

> *I am very lucky with the OT [occupational therapist] I had, they jumped through hoops to enable me to get this chair which was just brilliant, but 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? (7-54).*

There was recognition that the high cost meant less people could have multifunction power wheelchairs: *...only the cost, if they were a lot cheaper more people would be able to have them (9-29).* The time the process of getting a multifunction power wheelchair took was seen as another barrier to independence and there was a perception that ACC (Accident Compensation Corporation) clients received faster provision than MOH (Ministry of Health) clients.

> *I get a bit hot under the collar when it is the whole inequity thing between ACC and the MOH, you know when you think about it ACC clients can get a new power chair quicker, I had to wait a whole year from start to finish, a year is a long time when you cannot be at your full independent best (4-85).*

Other stakeholder's attitudes or actions were seen as important factors that impacted on the outcomes. *You have to look at the person as a whole and I was really happy that my OT [occupational therapist] really looked at that and really took the time with me to find a wheelchair that would suit me…(7-45)* in contrast to *... The powers that be wouldn't justify that (5-21).*There was an acknowledgement of the need for understanding.

> *Therapists wouldn't be there if the clients weren't, and the technicians don't always setup the chairs well, especially when people are non-verbal and they can't say. Technicians need to have more empathy and a bit more understanding of people's needs (1-40).*

One participant recognised they had very individual needs that required more than just a straight forward solution and felt this impacted on the working relationship.

> *I think the therapist who was dealing with me got so sick of me not fitting into the mould but she was going to give me something to shut me up and that was it and she eventually handed me over to someone else and said she was working in a different area, I thought "yeah, sure!" (5-43).*

Another barrier to independence was limited knowledge of what was available and possible: *I was desperate because if I hadn't found this chair I would have stayed with my original chair, I couldn't see anything that was better(1-35).* This problem of lack of knowledge was perceived as not just being on the part of the consumer: *...the biggest thing I found was having to learn what was out there, the OTs [occupational therapists] don't seem to do the research before they come to see the person (1-38).* The lack of knowledge of options, cost and choice impacted on the wheelchair outcome: *I'd love a stand-up wheelchair but I wouldn't have thought it would be funded (8-34).* The importance of being informed and having choice was highlighted in this statement:

> *I had a more standard power wheelchair and 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 and I wouldn't have needed all the stuff of the other one (1-2).*

Equipment shows were mentioned as being a useful place for being able to independently look at what was available, increase product knowledge and even being able to try out a demonstration model.

I tried the chair at an equipment show and then I got talking to this American chap that was there that had one and had had one over in America and he said it just changed his life too, it is such a good chair, he has had two and he was on the second one (1-37).

One active participant who needed to function alone and independently everyday was very frustrated with equipment failure and breakdown.

.... to have someone come into fix it and take it all apart and then look at you and say "we need to take this back to the workshop" and you suddenly think "you do that and my life stops for the next 24 hours, or 48 hours and I can't do anything ... and you're just hanging around waiting for people (4-43).

The availability of trial equipment and even trial equipment in the correct type or size was an issue for participants.

I did (trial a few different chairs) and so for a few weeks I could do all these things and then they (therapist, supplier) take it off you, I could do all these amazing things for a few weeks, and then I couldn't do them anymore until I get another one (4-86).

Even getting one to trial was a job in itself, we only have one they (therapist, supplier) said, when they bring out a trial chair that can't fit you, you have to assess if it is going to suit you or not, and take a big gamble (5-45).

One participant took their time to trial a number of options so they could identify the most suitable wheelchair.

Compared to all the other chairs I tried and look I tried a lot of chairs, so I could write a book on the chairs I trialled before I settled on this one, and I have had this one for two years, and I am hoping it is going to last me a few more, um, I would say this is one of the best because of the features: because of the arms, it also puts me into a comfortable stand whereas some of the others didn't, they put pressure on the wrong parts of me which I just felt weren't comfortable, and that obviously comes down to each individual (7-36).

The importance of trialling different options thoroughly to identify the best wheelchair was stressed by this participant: *I trialled three chairs, I put them through their paces because I didn't want to get the wrong one, I wanted to make sure (8-28b).*This is because the user is the biggest stakeholder, they are the most impacted by a poor person- equipment-environment match. Many barriers to independence have been identified including unreliable equipment, breakdowns and being 'stuck', heavy weight, on-going repairs, lack of power backup wheelchairs, availability of trial equipment and parts, limited funding and limited knowledge and experience.

Theme 5: Personal and Social Identity

Participants reported an impact on their personal and social identity attributable to their multifunction power wheelchair use and felt the equipment was very much part of them ... *an extension of my body (5-1).* One participant experienced an increase in positive attention and interaction when standing in public compared to being ignored when they were sat in their previous power wheelchair:

> *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 you know…people tend to ignore people in wheelchairs when you are out in public, I am just talking generally, but now I stand at the bar and guys will come and chat to me about the wheelchair and it is quite a cool talking point rather than trying to ignore me because they don't know what to say so sometimes it's quite cool as well (7-22).*

They felt more confident about meeting people: *I think just meeting people and hanging out, it is quite nice to be able to stand up and hug people which I think is quite nice (7-24).* They did not wear a chest harness so there was no barrier or restraint to freely hugging. The benefit of not having to wear an upper body anterior chest belt was appreciated for its aesthetic benefits to appearance.

> *I have a stand-up wheelchair and it has recline [recline back function] on it. Its defining feature was the armrests which you can move up into position when you need to brace but*

you can place them out of the way and it can act as an armrest which is its best feature because it means I don't actually need a safety chest belt which I don't think looked sexy to be honest (7-1).

… as a whole this wheelchair really suited me and I think chairs have to suit your lifestyle and your personality because they become your fashion accessory as well and your daily thing that gets you around and they need to match that (7-45).

The same participant mentioned the time it took to adjust to a new wheelchair as the old wheelchair was very much part of them *I am very comfortable in the chair; it took me a wee while to adjust from one wheelchair to another because obviously they become your old friend (7-37).* They also stated they wanted to be seen, not their wheelchair.

I didn't want a wheelchair that makes me disappear in it, if that makes sense because some chairs are so bulky that you just disappear in it and don't see the person. I wanted a chair that was supportive and everything else but was just a chair and you could see me (7-4).

A number of participants mentioned that people stared at them in public: *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 (10-31).* The same participant despite having limited mobility in a manual wheelchair preferred to use it in public: *Mainly use manual wheelchair, it is not as heavy, a lot easier to put into car, and you don't stick out so much in public, people don't stare as much (10-25).* However it is not possible to raise oneself up in a lightweight manual wheelchair and you remain in a low seated position compared with this participant's experience: *If someone is looking down on me I can get up to their height which is awesome, and with some kids you can get lower down to talk to them (9-15).* In contrast one participant was very comfortable with curiosity and questions from members of the public.

It is not just this particular power chair but I have found with a power chair it draws the attention of men, and what makes it go, and the batteries and that, do you charge them? You know interest like that, how does it work? And small boys are particularly interested in how it works, what makes it go, so I usually make a point of explaining it to them even

though their mothers go "come away, come away." If he wants to know I will tell him about it (5-31).

One participant had this comment about other wheelchair users: ... *you can get the wrong impression of who they are [wheelchair user] and only once you start talking to them you think: " man that wheelchair doesn't really suit that person" (7-46).* There was also comment about what other wheelchair users think of their wheelchair: *When mates who use chairs, see the chair they can't believe all the bits and pieces on it (8-28).*

In summary personal and social identity were important considerations for participants.

Theme 6: Well-living

There were many and varied experiences shared by participants of a more active involvement in their individual lifestyles. These were mainly positive around successful acquisition, improved mobility, increased safety, increased independence, being able to stand or use seat elevate to communicate and to see as well as improved identity. All the participants had examples of improved life experiences due to their multifunction power wheelchair use as this description illustrates:

I do enjoy travelling, going to concerts and that's another great thing, for the first time I was in the mosh pit because I could stand-up and I was the same height as everybody else, so I could really be amongst my friends and not in a separate area for wheelchairs, which was a really nice experience, really, really cool. I could be with all my friends and I could be amongst it with everybody, I don't know how you want to phrase it, it gave me the 'great experience' (7-19).

Well-being was improved for all the participants but it was more than being well. Well-being has been criticised as a measure because it is a retrospective judgement influenced by mood or state of happiness (Mathews, 2012). Participants were living well which lead me to interpret the participants' experiences by coining the term "well- living." A dictionary definition of "well"

(Oxford University Press) includes words such as "in a satisfactory or advisable way" and a definition of "living" includes words such as "having life." It is proposed that "well- living" provides a useful concept that reflects what the participants were describing and can be seen as a combination of well-being (Hayward, Taylor, 2011) and well-doing. "Well-living" is defined as self-determined, satisfactory living. Participants were meeting their own expectations. Therefore all the positive findings and themes identified in this study have a natural grouping together under "well-living". Well-living can be achieved when mobility, function and environmental factors are addressed effectively such as expressed in the next statement: *A lot more relaxed when you are out. So nice, no worries when I go out. There are still limitations but a lot less limitations (1-7).*

Findings Summary

This chapter has presented the participants' statements and described the key themes that have emerged from the interviews. The findings show what is important from the perspectives of a small group of adult users of multifunction power wheelchairs and also describes relevant experiences that every stakeholder especially potential users of multifunction power wheelchairs need to consider. To this end the 'voice' of users is captured and revealed.

This study has important implications for the effective provision and use of multifunction power wheelchairs.

In the following chapter five, each theme will be discussed in-depth in relation to the 'voice' of users and past and current literature and practice.

Chapter 5: Discussion

Introduction

The answers to the research question: what are the perspectives and experiences of adults using multifunction power wheelchairs in Aotearoa, New Zealand, has been the purpose and focus of this study. The previous chapter has described the findings using direct full quotations from the participants and explanations and interpretations. This chapter will now discuss the findings of this study. Although the findings cannot be generalised they are examined in relation to existing literature, identifying where they align, and what is different. The themes are explored in further depth in order to further clarify the study's key findings and the implications these may have for users and occupational therapy practice:

Power mobility is the basis for getting to where the living is, so this was considered first. However, the environment can be a facilitator or an inhibitor to mobility and engagement in living, so this was considered second. Thirdly, the functionality of power wheelchairs enabled people to engage in the occupations of daily living once the user is able to access the relevant environment. Fourthly, independence in meaningful occupations made possible by the improved mobility and functionality was highlighted as important by all participants. This included social independence. However, there were barriers to independence identified. Fifthly, the impact on personal and social identity was an important consideration. Finally, the culmination for participants, of having an effective multifunction power wheelchair available for use within an inclusive environment was 'well-living,' the sixth theme. This flow of themes from power mobility to the actualisation of well-living is shown in Figure 1. Flow in this instance means to move and progress, each thematic experience or perspective contributing and leading to the next as they are all interconnected.

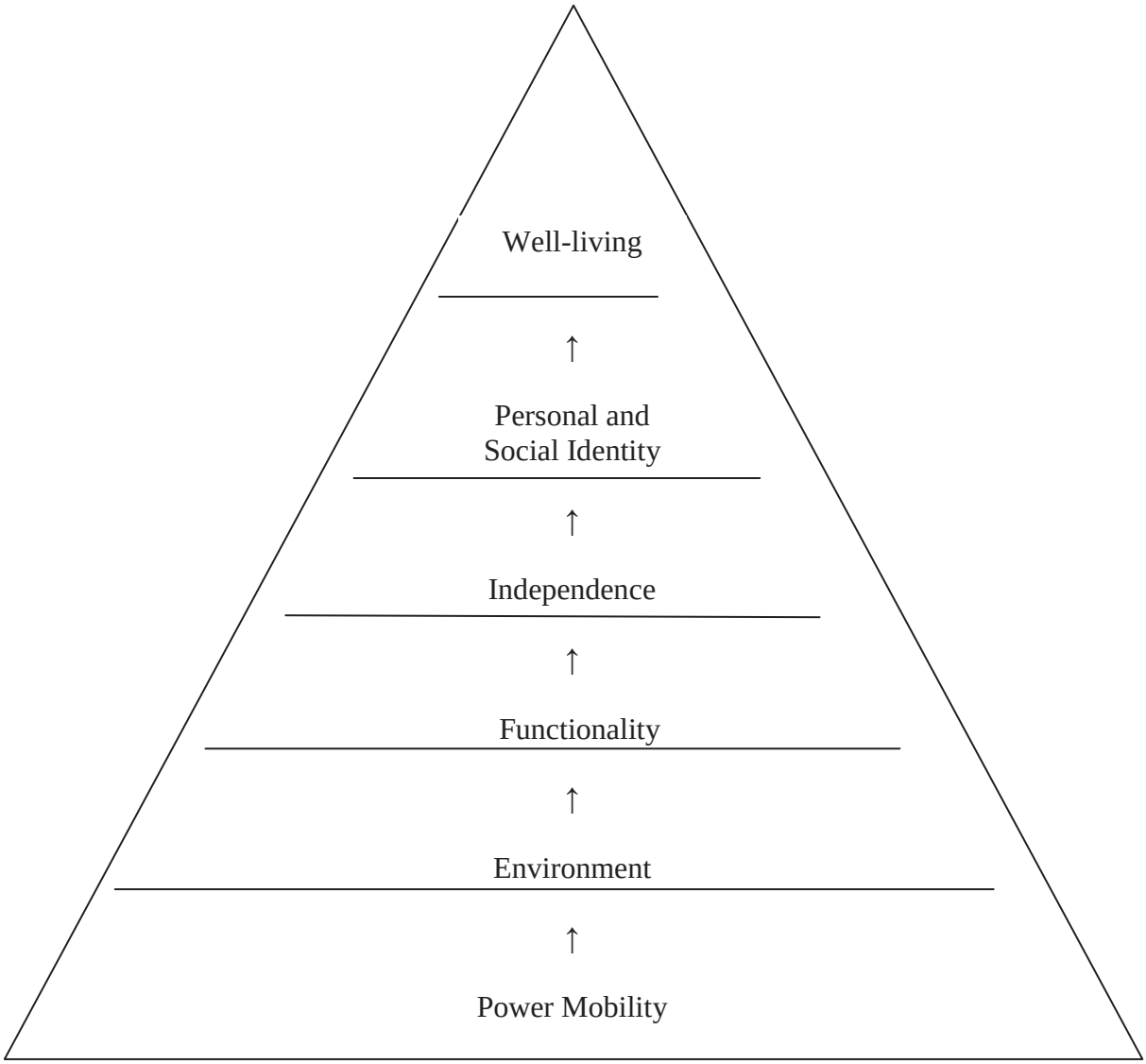

Figure 1: Flow of Themes: Well-living actualisation for power mobility users.

Power Mobility

Improved mobility:

Improved general independent mobility and moving around under one's own volition (in multifunction power wheelchairs), was an important benefit expressed by the participants (refer figure 1) in this and other studies (Boss & Finlayson, 2006**;** Bunning et al, 2001; May & Rugg, 2010). Persevering with other modes of mobility can sometimes increase fatigue, be inefficient and increase the likelihood of accidents and injury. For example, one of the participants in the study had suffered from multiple ankle fractures (as their primary condition had deteriorated) and reported they did not miss walking at all, and two other participants had shoulder trauma from

overuse before using power wheelchairs fulltime. Bayley, Cochran and Sledge (1987) found high intra- articular pressure in the shoulders of people with paraplegia doing lifting transfers which contributes to shoulder injury. Therefore effective transitioning to powered mobility needs to be discussed and considered, as participants reported significant impacts on their health. Improved mobility was achievable because of the multifunction power wheelchair, which generally assisted with better environmental access for daily occupations to occur.

The impact of multifunction power wheelchair use goes far beyond just moving from point A to point B (Mortenson et. al., 2005). Improved mobility comes from having the right equipment. Often this had to be individually determined. Having the right equipment enabled people to participate. The participants in this study had significant levels of physical impairment and hence the mobility and functionality gained made a substantial difference. Autonomy through independent mobility was highly valued, so that participants could freely participate in their lives, especially to fulfil social roles such as parent, friend and worker. One participant enjoyed being able to move much faster, further and longer than walking friends and the speed had in fact made this participant 'super-abled' (Mullins, 2010) as opposed to disabled. This is an exciting and positive change in perspective for wheelchair users.

From a technical perspective, mobility was also improved through the use of a multifunction power wheelchair because of its higher specifications including: stronger frames, bigger motors and batteries, and advanced electronics. For the participants, the drive quality, distance and safety were enhanced especially during outdoor mobility. For example with better weight distribution one participant reported less skidding on wet and slippery paths around the workplace. Wheelchairs with the weight of the participant sitting well centred (centre of gravity) over their motors and drive wheels had less wheel spin (Denison & Gayton, 2000). Therefore the position of the person over the wheelbase is an important consideration for therapists and technicians involved in wheelchair setup. This may contribute significantly to an increased feeling of stability and safety (as expressed by one participant who had lower limb amputations) which will enable and encourage greater participation.

Barriers to mobility

Multifunction power wheelchairs can both enhance mobility, but also compromise it. Unreliable equipment, breakdowns and repairs significantly reduced independence for some of the

participants and provoked strong emotions of frustration and anger. This was related to the complete disruption of their lives and subsequent loss of 'control.' This is because the participants had significant levels of physical impairment so when the equipment failed they could do little or nothing to reduce the impact. Some participants found an increased level of technology could mean an increased level of repairs compared to their previous more basic wheelchairs.

Wheelchair breakdowns meant participants were 'stuck' in a range of places from their home, to their car, the cinema, and even on a hill. Breakdowns can cause major disruption and inconvenience in users' lives. Participants also expressed concern about the effect on their loved ones having to come to their rescue or push them around. Participants did not want to have to ask for or accept the high level of assistance necessary when equipment failed, for example assistance to get to the toilet. With the failure of the equipment they returned to experiencing a high level of dependence because of the level of disability imposed without a functional power wheelchair; often when support systems have been disestablished as they were no longer required when the equipment functions. Thus, as identified by Batavia and Hammer (1990), the repairability of multifunction power wheelchairs is an important factor in ensuring independence. A 2012 American study found there was an increasing level of wheelchair breakdowns (Worobey, Oyster, Nemunaitis, Cooper & Boninger) at 53 % compared to 45% in 2006 which the researchers attribute to a decline in quality as standards such as RESNA are not enforced. Similarly New Zealand has an unregulated wheelchair market. A British study following up indoor-outdoor power wheelchair users found there was a high level of component failure. Therefore taking advantage of technology developments was not without risks and on-going monitoring and support is recommended (Frank et al, 2000). This means occupational therapists and stakeholders need to place more emphasis on the longevity of solutions considering criteria of durability, reliability, repairability and availability of backup power wheelchairs or assistance for users and consider not just current but also clients' future needs.

The heavy weight of multifunction power wheelchairs was also potentially a positive or negative factor for participants. For instance reduced mobility can occur on soft terrain because the weight of the wheelchair increased the risk of getting 'stuck'. The combined weight of the user and the heavy multifunction power wheelchair also made it unsafe for other people pushing participants in the event of a breakdown because of the risk of injury. This leads one to question whether

multifunction power wheelchairs could be developed that are considerably lighter and more manageable? With the comments voiced in this study, together with information shared with manufacturers, new technologies may develop which would allow wheelchairs to be made with lighter componentry and therefore greater mobility. Thus, users must be included in the evaluation of technology as they directly interface with the power wheelchairs. They are an important source of design criteria (Lafuente et al, 1998). However, there has been little published evidence of user participation (McCreadie et al., 2002). This indicates the need for further published research into users' experiences.

Environmental Factors Affecting Mobility

People are inseparable from their occupational environments and contexts and so the environment in which the multifunction power wheelchair is used is essential to consider. Much of the environmental design for wheelchair access has been around a more active wheelchair user in a much lighter wheelchair. Hence weight limits of lifts, widths and design of doorways, passages, pathways may not be suitable for this newer group of users, who require equal independent access but are using more complex equipment. Flexibility, so people can keep participating and interacting within their environments is an important consideration, especially when people have a slow deteriorating condition, otherwise people can experience a loss of independence over an extended time period.

Disability and aging are not static and people change throughout their lifespan and are very individual in their rate of change. Results of a randomized controlled trial of the effectiveness of assistive technology and environmental interventions in maintaining independence for frail elderly people showed that the rate of decline can be slowed (Mann et al, 1999). The different environments of home, school and work, outdoors and transport will now be discussed.

Home

Home and participation in home life was naturally very important to participants (Rowles, 1987; Hamilton, 2004). People's home environments needed to have level or ramped access and adequate space to move. The large size and dimensions of the multifunction power wheelchair were important considerations. To prevent damage doorways and passages needed to be wide enough for multifunction power wheelchairs to pass through easily and participants found door

frames were a common area to get damaged. Damage or "destructiveness" to the home environment caused by using a power wheelchair was also a negative factor identified in a study by Boss & Finlayson (2006). Small or confined areas were difficult to negotiate and there was a sense of mastery expressed by participants when they were successful. Differences in manoeuvrability do exist between similar power wheelchairs (Pellegrini, Bouche, Barbot, Figere, Guillon, & Lofaso, 2010) therefore thorough user trials in environments of use are important.

Mid wheel drive power bases were the most commonly used and are the most manoeuvrable as they have a decreased turning radius. This is in contrast to a rear wheel drive power base which has the largest turning radius (Koczur, Strine & Peischl, 2000). Participants hoped that their power wheelchair would increase independence but poor environmental planning and design hindered full occupational engagement (Pierce, 1998; Smith, McCreadie & Unsworth, 1995). For example participants found soft landscaping around the home such as wet grass challenging, and indoors carpet reduced manoeuvrability and was harder to drive on than smooth floors such as wood. Accessing the wet shower area was a challenge to keeping the electronic controls dry for one participant who liked to shower independently. There was reluctance to have the bathroom modified to a wet area shower but changes were probably inevitable with a progressive condition. However, kitchen modifications managed to be avoided because the power wheelchair had seat elevate function, which meant cupboards and standing height benches could be accessed. Well-designed lifetime homes with level access and good circulation space are important (Hall & Imrie, 1999; Imrie, 2003), and this benefits everyone not just people that happen to use wheelchairs. This also allows for future proofing the home to allow for developments in technology. Building accessibility standards are now freely available and should be used. Inclusive design benefits everyone throughout their lifespan, therefore features such as access in and around homes needs to be mandated.

School and Work

Work places can be more accessible with high low or standing functions not just physically such as vertical accessibility to access shelves, but visually and socially, for example seeing around the office and interacting. Unfortunately the weight of the multifunction power wheelchairs could be a barrier to using small building lifts, and one participant had not just had one but three 'horrendous' experiences of being trapped in lifts at a school, and at an office block. The weight limits of these lifts need urgent review, and unless legislation is mandated for accessible building

design that is inclusive of a range of mobility bases now used access issues will continue to impede people's full occupational engagement, participation and contribution in society.

Outdoors

This study showed multifunction power wheelchair use enabled increased access to a range of outdoor environments by all the participants. To achieve social inclusion autonomous mobilising outside the confines of home is essential, and this also helps slow or prevent functional decline, increase the level of social and leisure activities, and improve general quality of life. Outdoor environments were mainly accessed by participants for work, shopping, social and recreational purposes (parks, spectator sport) akin to their fellow citizens. Users reported access into shops could be difficult because of threshold lips, especially with aluminium joinery, and also the amount of shelving and stock blocking movement inside. One participant explained access hadn't changed significantly because of upgrading from a lesser power wheelchair to a multifunction power wheelchair, because accessibility was an on-going issue, and they had always asked about wheelchair accessibility. This is similar to a UK study of city accessibility (Bromley, Matthews & Thomas, 2007). Again policy and legislation needs to be used to ensure inclusive design of all built areas.

Poor access was also the finding of other studies of users of powered mobility (Boss & Finlayson, 2006; McMillen & Soderberg, 2002). These findings reflect the social model of disability where it is the environment that creates the disability not the individual's impairment (Oliver, 1990). A randomised controlled trial of an occupational therapy intervention (using provision of information, approaches to overcoming fear, and use of aids and appliances) to increase outdoor mobility after a stroke showed an increase in the number of outdoor visits (Logan et al, 2004), yet an inclusive environment is still required to really open up the possibilities. The weight of multifunction power wheelchairs on soft terrain such as sports fields, and managing thresholds was a problem. However, one study found power wheelchairs were better at negotiating rough or demanding terrain compared to an alternative such as a manual wheelchair with power assist wheels (Giesbreht, Ripat, Cooper & Qanbury, 2011).

Inclement weather conditions were also challenging as users wanted to avoid getting the chairs and electronics wet as well as keeping themselves dry. The rain fall is high in the Auckland

region however it is a temperate climate compared to other countries which have more extremes of temperature to deal with. Weather conditions affecting outside usage was identified as an issue in other studies (Brandt et al, 2004; Frank et al, 2000; May & Rugg, 2010). This means access to convenient transport is important and will be discussed next.

Transport and Travel

Transportation was an important issue to participants, especially since a standard vehicle could not be used because of the difficulty of physical transfers and the size and weight of the multifunction power wheelchairs. It was expensive to buy a modified vehicle or to use mobility taxis. This cost was beyond the reach of a number of the participants interviewed and impeded their ability to access the community for work, family and other social commitments. The New Zealand Human Rights Commission is part of a monitoring body, to improve access to the built environment and public transport (2009). A British study also highlighted the issue of funding modified vehicles (Dewey et al, 2004) and all 23 participants reported difficulty with transport. Mobility taxis, as well as being expensive, were not always available to participants at the times required due to school and routinely contracted runs. Scheduling was mentioned as a problem in overseas studies as well (Reid et al, 2003). Another British survey of the transport of power wheelchair users (Belcher & Frank, 2004) showed that transport was an important issue to participants, 20 percent of respondents felt unsafe due to inadequate clamping and restraint. Public transport was not a readily available option in all areas of Auckland as many participants lived some distance from train or bus stops and only one participant used public transport because of their more central location. The other disadvantage is that public transportation is timetable dependent, not always conveniently scheduled and more time consuming and awkward to use than having access to personal transport.

The weight of the multifunction wheelchair made using van hoists and small lifts in buildings impossible or difficult due to the weight limit being exceeded by the combined weight of the multifunction power wheelchair and the user. One busy participant who worked part time and parented young children was especially affected by building lift limitations and breakdowns. They also needed to replace their vehicle and hoist to accommodate the heavier multifunction power wheelchair but were constrained by available funding.

The weight of the multifunction power wheelchairs was also a problem in aeroplanes (especially smaller aeroplanes that fly into provincial centres), and in addition hiring wheelchairs at the destination would not be able to have the correctly configured seating. Better positioning in a wheelchair can impact on comfort and the ability to forward reach and hence functional ability (Amos et al, 2001). Portability was another important criteria identified by a panel of consumers (Batavia, 1990). They defined it as the extent to which equipment can be readily transported to and operated in different locations, and whether the length of battery charge allows this. Other relevant factors to consider also included can the power wheelchair be easily transported in car, train, aeroplane, and be powered up if necessary, for example, with an on board charger. Hopefully as technology develops these issues of effective, affordable transport and travel will be addressed. Currently, multifunction power wheelchairs are the heaviest of the power wheelchairs available because of the weight of the power functions but the functional benefits outweigh the disadvantages as discussed next.

Functionality

There were many benefits of using power wheelchair functions expressed by participants such as improved mobility, energy conservation, fatigue management, injury prevention and increased physical access. Functionality was possible when participants could mobilise in accessible environments (refer figure 1).Access was not just in a horizontal direction but in a vertical plane as well. Comfort was a factor reported by some participants and also a criterion deemed important by a consumer panel (Batavia & Hammer, 1990) as well as an important issue in other studies (Weiss-Lambrou et al, 1999). Similarly increasing seating comfort through ergonomic interventions such as tilt and recline has been shown to increase productivity in the workplace (Wilson & Corlett, 1995)

All the participants interviewed were very clear about the power wheelchair functions they required and most of the participants used the functions in combination. Having the power functions available gave the means to work out an effective way to do things. Sometimes it was just by virtue of having the functions that lead to a useful solution emerging rather than it being immediately obvious to them at assessment, trial or provision stage. There was also the ability to engage in new situations, previously inaccessible, and with the new confidence and knowledge of how the wheelchairs operated participants were actively searching out new opportunities. Human beings can adapt to change and so ‘adjustability’ and adaptability within systems helps people to

journey through life fully engaged without restrictions imposed by their equipment (Batavia & Hammer, 1990; Buck, 2002). Introducing increased functionality early would prevent the loss of independence experienced by some participants while they waited for provision of their multifunction power wheelchair.

Reducing pain, pressure, increasing comfort and the ability to stretch out and rest were also important to participants. Inconceivable to people who are free to move would be the thought of having to be immobilised in one position for long periods of time, but this is the reality for many wheelchair users who cannot move themselves. The discomfort of static daily wheelchair sitting can be a chronic problem (Monette, Weiss-Lambrou & Dansereau, 1999) which can lead to contractures, joint limitations, oedema and pain. The length of time a person can remained seated can be increased if a person can move and adjust their body position with power functions (Cooper, Dvorznak, Rentscheler & Boninger, 2000) as reported by participants who were in their wheelchairs most of the day. This is in contrast to prolonged static sitting in a wheelchair which can be considered a contributing factor to curvature of the spine or scoliosis (Kinali, Main, Mercuri & Muntoni, 2007) and also poor respiration (Massery, 2010). Multifunction power wheelchairs offered dynamic sitting which enabled improved digestion, respiration and circulation as well as function as reported by participants.

Seat high-low, was the most remarked upon function which facilitated independence. Seat high low helped compensate for limited joint ranges of movement or muscle weakness; for example to compensate for weak arms, to get dishes out of the dishwasher, access the sink, bench and cupboards, cook meals, use light switches, toilet transfers, car transfers and getting washing out of the washing machine. It also increased social independence which was significant and will be discussed under independence.

Different individuals have different needs and uses for the power functions, for example with the use of tilt. One participant with a history of pressure areas mainly used tilt to frequently change the weight bearing pressure from their bottom to their back. Another participant used tilt to assist with head positioning due to neck weakness and to assist with functional arm movement. A further participant would only use tilt when they were out and about on sloping terrain. From a safety perspective it is imperative people have power tilt if they are mobilising outdoors to tilt back to shift the centre of gravity and balance, increase stability and prevent falling forward or

out of the wheelchairs, especially with no seat belt (Greene & Roberts, 2005). Falling from the wheelchair face first onto the ground was the experience of one participant who had not used tilt on a slope and a near accident for another participant on a steep driveway. Safety is an important consideration. In a Canadian study mishaps had occurred in 15 out of 113 users (13 %) which included tipping from the chairs and falls during transfers (Frank et al, 2000). Tilt has many safety and functional benefits. Training in the safe and effective use of power wheelchairs is important and this can be naturally addressed through occupational therapy which considers the individual user and their occupations within their own environmental context.

Recline used in conjunction with tilt enabled participants to stretch out and rest. The open hip to back angle improved their posture and stability, accommodated weak trunk control, increased comfort and sitting tolerance so they were able to be up and actively engaged in living for longer. Tight hip flexors are a common problem with people static sitting for extended periods. Recline may help lessen this by providing a more open hip angle especially if people are sleeping in a flexed side lying position at night. Exactly how long or frequently recline should be used to this end is not known but there is a growing awareness of the importance of postural management and the times spent in constructive or aligned postures and destructive positions. Recline was also mentioned by participants as being useful at the doctors, hairdressers, dentists, dressing and even sunbathing. Recline and elevating leg rests were the two preferred functions by most of the 79 people with tetraplegia surveyed in the United Kingdom (Curtin, 1993). Anecdotally recline is a function that is generally not provided on power wheelchairs as frequently as power tilt in New Zealand (refer Appendix 1). However recline can really improve comfort and sitting tolerance so participants did not have to return to their bed or resort to pain medication. One participant found the use of recline reduced back pain during periods of prolonged sitting at work. This has also been shown in a study of users with spinal cord injuries (Samuelsson, Larsson, Thyberg & Tropp, 1996) and could be explained in ergonomic literature which states the gravity loadings of the thorax, head and arms imposed on the lumbar spine causes a slow decrease in spinal disc height over time (Wilson & Corlett, 1995). Posture deteriorates as the day progresses so regular stretches would assist in reducing this pressure and improving posture and comfort.

Elevating leg rests were used in an elevated position to help with leg oedema, to relieve pressure, to increase comfort and to manage pain. Participants found oedema was worse when the legs were immobile with the feet down. This is consistent with research into the lymphatic system

which shows that movement assists in the regulation of tissue volume and pressure by moving fluid back to the cardiovascular system (Lane, Worsley & McKenzie, 2005). Elevating leg rests were also used to passively stretch out legs and hamstrings by opening out the knee angle to give relief from pain and discomfort and if used in conjunction with other functions such as recline or tilt provide an overall position of rest. This correlates with an American study of twelve subjects who had their seat function usage recorded with a portable device (Ding et al, 2008). Tilt and recline functions were being used throughout the day to primarily improve comfort and subjects spent very little time in a totally upright position.

Standing to interact socially was seen as an enormous benefit in comparison to being immobilised in a standing frame or in a permanently low seated position as voiced by the one participant in the study who had power stand. The need for a standing frame was also negated. The back recline function was used for stable safe standing through allowing a slightly rear ward shift of the person's centre of gravity. Many benefits of standing were reported such as: being able to stand more frequently, move in standing, improved comfort, circulation, stretching and increased independence in many areas such as general working, banking, shopping, printing, faxing. These findings are supported in other literature (Anderson, 1994; Henshaw, 2002) and perhaps standing could be considered for more power wheelchair users. Especially, as this participant suggested for younger users, to improve compliance with and frequency of standing for all the physiological benefits that can help counteract physical inactivity (Sandler & Vernikos, 1986) as well as the many social benefits.

Importance of independence

Every participant in the study reported an increase in independence in a myriad of life activities, attributable to their multifunction power wheelchair usage. This was a major consideration for the participants of this study and therefore an increase in independence is the first subtheme. Whilst the contexts and the reasons for independence varied considerably, it was foremost in participants' minds especially social independence, the second subtheme. This potential for increased independence did not come without its own associated challenges or barriers, the third subtheme.

Increased independence

The key finding from this study was that independence was very important to all the participants. This is consistent with other studies of wheelchair users (McMillen & Soderberg, 2002; Pettersen et al, 2006; Sapey, Stewart & Donaldson, 2005), However, in this study, the range of disability was broad and the benefit that the client perceived was highly individual and not necessarily proportional to the level of disability. Some studies suggest that individuals with moderate impairments achieve the most positive functional outcomes (Brandt et al, 2004, Frank et al, 2000; Hardy, 2004, Korner, 2004). Whilst the levels of functional outcomes were not measured, the levels of reported sense of achievement were high, and were not linked to the level of impairment. It was notable that even small functional gains for a most severely disabled participant gave a huge boost to their feeling of independence and their expectations of themselves. As they described in detail, the experience of using the multifunction wheelchair tilt function to move their hand to use the phone and the computer, which enabled them, in their role as matriarch, to organise a large family gathering. The development of technology was not necessarily prescriptive in how it would be used, participants explored their new abilities to a greater or lesser extent and at different rates so no two users could be considered alike other than all welcomed the possibility of facilitated independent movement and their autonomy to use it as they wished.

In this study, total independence was not a goal for any of the participants, indeed total independence is a fallacy for any person as humankind is interdependent on each other and technology. For example assistance was still required for some participants with plugging in to charge batteries (power wheelchair batteries generally require nightly charging), and transferring to and from the multifunction power wheelchair. However these were not raised as significant issues by any of the participants. Rather, for the participants, engagement in meaningful occupations was considered more important. Perspectives on independence are often individual and culturally or socially relative (Hocking, 2009). Thus, it is highly important for occupational therapists to identify and reflect on what is most important to the client. This is in line with person/ client centred practice (Law, Baptiste, Mills, 1995; Townsend & Polatajko, 2007). This is not always easy given the contextual (person, environment, occupation) tensions between the myriad of stakeholders (including the therapist), resourcing, service expectations and the client's needs (Wilkins, Pollock, Rochon & Law, 2001). This has been referred to as "moral contracts of

intervention" by Golstein-Lohman, Kratz and Pierce (2003, p.247) where therapists are making "contracts" with clients, funders, employers, other professionals and themselves. For example in private for profit health care (such as ACC provider) the focus can be on episodic, fast and efficient assessment potentially limiting contact, as opposed to a client needs based process working in a not for profit setting (such as public health). Or a therapist using the client's medical diagnosis or focussing on the physical component of postural issues as the primary focus as opposed to a primarily occupational focus. Person centred practice honours the moral contract with the client as has been experienced by some participants in this study resulting in effective outcomes such as the use of a power standing wheelchair.

Social Independence:

For the purpose of this study social independence is defined as the enactment of social skills in context (Doble & Magill-Evans, 1992). For example, and most significantly, high low or standing function was used by participants to position themselves closer to standing height for social interaction and conversation. This was reported by participants to be especially useful in compensating for speech language issues such as dysphasia, low voice volume and hearing loss. In addition this also aided vision, eye contact, body language and concentration which enabled the execution of social interaction skills such as sending, acknowledging, timing and co-ordinating conversation (Doble & Magill-Evans, 1992). Therefore high low and standing functions gave participants social independence.

High low or standing function enhanced social reciprocity and empathy, and other psychosocial benefits such as general increased confidence and motivation. As one participant expressed it: '…st*aring at people's belly buttons…'* prevented independent social participation. Participants preferred being able to physically relate at a relatively similar height, which helped promote a feeling of equality, inclusion and broke down socially constructed barriers. Subsequently this helped to reduce the feeling of stigma, lost status or being seen as '*mentally incompetent'* and dependent because one is sitting low down in a wheelchair. The impact on social identity and independence is likely to be greater than therapists often realise as evidenced by the participant's statements and my observations.

Whilst most literature on power wheelchair use referred to a broader interpretation of social outings within the community as opposed to the enactment of everyday social interactions, occupational therapists need to place more importance on the individual's specific social needs and opportunities and what this means to the person as indicated by the participants. It is integral to human nature to be able to freely interact with people otherwise one can become isolated and lonely (Kasser & Ryan, 1999). The participants expressed that social independence is as important as physical independence. Socially engaging in occupations, such as attending concerts with friends, is as important as being able to engage physically. Social participation is necessary to support relationships and well-being. Although many wheelchair users have not been able to stand or elevate up to standing height until recently does not mean this is not an important outcome.

Barriers to independence

Independence was enhanced through the use of power functions but also compromised with breakdowns and repairs which significantly reduced independence for some of the participants especially when assistance was not readily available.

Cost, knowledge, skills, time, attitudes, actions, transitions and complexity were also posited as barriers to independence. The high cost and the capped or limited funding were expressed as barriers to independence by participants because choices and options for multifunction power wheelchairs, power functions, vehicles and transport were then limited. This had far reaching consequences for the participants in terms of lost opportunities for participation and engagement in occupations over their life span. For example this was expressed by participants as regret at being unable to prepare family meals for a couple of years to lost opportunities for social contribution and participation at functions. Time is a valued resource and something that cannot be reclaimed. Qualitative longitudinal studies considering occupational wheelchair use are needed.

Affordability was also an important criteria identified by a consumer panel (Batavia & Hammer, 1990). High cost was also mentioned in other studies as well as a concern about value for money (McComas, Kosseim & Macintosh, 1995). Thus, cost can limit access and choice and not many

people in the general New Zealand public would have the financial resources (Statistics New Zealand, 2012) to enable them to self-fund and maintain a multifunction power wheelchair. It is important that there are equal resources and opportunities to ensure all people can achieve healthy lifestyles (United Nations, 2006).

Some of the participants saw their own limited knowledge and the assessing therapists' lack of information about the types of multifunction power wheelchairs available as a barrier to obtaining the best option. There is a range of differences in how consumers value, understand and seek health related information (Maibach et al, 2007). Subjects in a study of individuals with multiple sclerosis acquiring and using power wheelchairs found they did not always find the most suitable power wheelchair the first time, and it was an on-going process (Boss & Finlayson, 2006). This could be due to a lack of experience and knowledge of the users and therapists. One way therapists could develop their services to users is through increased evidence informed practice (Tse, Lloyd, Penman, King, & Bassett, 2004) which includes critically appraising the research (Westropp & Masters, 2003), discussing the implications and engaging in research (Cusick, 2000). Currently there is a paucity of literature to support practice on this topic.

One participant recognised they had very individual needs that required more than a straight forward solution. This highlighted that adults are a very heterogeneous group and different mobility solutions are required for different individuals. The process of matching technology to an individual can be complicated (Boss & Finlayson, 2006). It needs to be person centered and can take a high degree of commitment to achieve optimal outcomes. Occupational therapy encompasses a problem solving process that works towards a future vision of what is possible (Robertson & Griffiths, 2012). To listen to the users' voice and understand their occupational vision is important (Gooder, 1997). Vision is what shapes people into the future (Mullins, 2009).

Participants who had unimpaired cognitive function had the ability to solve their own occupational problems or challenges and just needed the means of mobility to get on with their lives i.e. multifunction power wheelchairs. These participants had become expert users, as for some participants it was at least their fourth power wheelchair. Assessing therapists need to recognise these experts and should not presume to compete with a high level of user experience and knowledge. Taking an understanding position of assessor, facilitator, supporter, collaborator

and advocate would be more appropriate, than expert advisor. This is part of person-client centred practice.

Some participants mentioned positive experiences and outcomes with the client-therapist working relationship; others felt the therapist was the power holder and gatekeeper. There can be disparities between what the users and the therapists rate as important (Dewey et al., 2004). It would be interesting to explore the impact of occupational therapy on outcomes for users (Cohen, Fitzgerald, Trefler, Boninger & McCue, 2004). The style of therapeutic relationship participants experienced possibly varied and maybe explained by 'relatedness,' a process where the person receiving the service feels understood, respected and cared for, which can then impact on the outcomes (Ryan, Patrick, Deci & Williams, 2008). In New Zealand, at the time of writing, targeted training was mandatory and available for therapists assessing and accessing public funding of wheelchair and seating solutions (Ministry of Health, 2012). This aims to improve the level and depth of assessment knowledge and skills. The challenge for therapists could lie in optimising client participation in the process of obtaining solutions (Hedburg- Kristensson et al., 2006). In order to meet the needs of wheelchair users skilled, well trained and most importantly person centred practitioners are required.

The background of the user can influence their choice of mobility base and ease of use could be a factor in that decision. This resonates with this study where one participant in particular mentioned an unsuccessful trial experience due to the complexity of controls. Therefore information, time and practice are required to master technology and develop new habits of use. For example one participant described getting in the habit of using the elevating seat function. The transition to new equipment can be very disruptive and stressful for people (Batavia et al, 2001) and support, training and monitoring are required. An information booklet would be useful to backup and support demonstrations, training and verbal instruction (Jelier &Turner-Smith, 1997). Written information is essential for reinforcing spoken instruction and demonstrations when new technology is trialled or issued.

The challenge for therapists involved in the assessment and provision of complex power wheelchair solutions is how to achieve the best outcome for users. Evidence informed practice is important as well as involving the user in product selection (Minkel, 2000). There is a large amount of information and range of products available (Taylor, 1993) that have to be considered

and applied. On-going research into the efficacy of assessment service delivery, the resulting solutions and outcomes for users is required (Datta & Ariyaratnam, 1996). There is an increasing research interest in ensuring effective mobility solutions, and reducing equipment abandonment as evident in the literature.

Interestingly, no participants mentioned improved posture as an important outcome, however they were all observed to be sitting well. Effective posture is where the body weight is symmetrically distributed and tasks can be completed with the least fatigue. A totally upright sitting posture is not suitable for many tasks (Pain et al, 2003) and participants often need to be able to tilt or lean forward to function. This asks the question as to whether posture is an important factor for independence in the participants' eyes or whether it was not raised because their seating systems were effective and therefore not seen as a barrier.

A further barrier to independence, albeit temporary, was the time taken to complete the process of getting a multifunction wheelchair. This included the funding and trial process and one participant reported taking over two years of trialling a number of different power wheelchairs to reach the optimal solution. It is often difficult to assess whether a product best meets a person's needs unless it is used in context over an extended period of time. Therefore other users' experiences often provide some means of ascertaining or endorsing suitability (Batavia & Hammer, 1990). This further supports the need to involve the user's voice in the whole research process. My experience and anecdotal evidence suggests sales representatives and peers, such as people in support groups, who are wheelchair users themselves can be helpful to users because they have the lived experience. Users often access the internet for information and their own online networks for expertise.

Stakeholders' attitudes and actions could be a barrier to independence, and there was a request from participants for more empathy and understanding from all services involved in the funding, provision and on-going maintenance of their wheelchairs. This could be achieved through broader service knowledge of users' perspectives and experiences (McMillen & Soderberg, 2002). Everyone involved in a users' life has an effect on outcomes (Scherer, 1996), therefore everyone's focus needs to be on client centred outcomes.

Personal and Social Identity

Individuals in society, such as the general public of Aotearoa, New Zealand, like to self-determine their identity. However identity can be affected if one is not able to self-determine the look of their body and the wheelchair. The multifunction power wheelchairs gave participants the opportunity to have better looking wheelchairs by nature of the fact that they are of higher specification and quality, thus enhancing self-identity.

Moving to a deeper more personal note the concept of "embodiment" (Winance, 2006) was alluded to in the descriptions participants offered, for example "the power chair is an extension of my body." The wheelchair is an essential part of a fulltime user (Batavia, 1998) just as legs are essential to a differently abled person .i.e. someone who can walk. When you compare what legs are able to do, the limitations of a power wheelchair are obvious. Legs are compact, they can swivel on their feet, they can take you in horizontal, angled and vertical planes and they can be fashionably attired in different ways.

Posture and the style of clothing worn can be impacted by the style of wheelchair, which in turn affects people's appearance. It is well documented that prolonged static sitting and the inability to move or change position visibly affects people's posture. Overtime people can collapse forward and down due to weakness and gravitational pull. The ability to move one's self therefore impacts on personal identity.

Improved body image and aesthetics were important to some participants. They felt the equipment was very much part of them, suiting their lifestyle and personality with one participant even going so far as calling it a "fashion accessory." An improved social identity led to an increase in positive attention and interaction in public. Papadimitrou (2008) highlights an interesting paradox: "the very accomplishment of becoming en-wheeled and of achieving re-embodiment by "doing" can stigmatize users since it is this very accomplishment that brings them out in public where they are seen as unable to "do"." (pp. 699-701). All the participants were aware that being in a multifunction power wheelchair had an effect on their social or public identity. They reported a range of reactions from people staring at them and obviously wondering about their mental status to an increase in positive attention. Multifunction power wheelchairs

can enable/re-enable a positive personal and social identity if they are an embodied part of the person.

There was a sense that participants were sometimes thrust into a disabled role that they didn't want to embrace because they were in public. In an American study users had reported negative societal attitudes ranging from people staring, to children being frightened, but that the negative social attitudes became easier to adjust to and deal with over time (Boss & Finlayson, 2006). One participant welcomed children's questions but found the parents took the children away. Interestingly this was mentioned by a user in a Swedish study who put it down to the insecurity of the parents and likewise did not mind the children asking questions (McMillen & Soderberg, 2002, p.179). The New Zealand Government is investing in programmes such as the Making a Difference Fund to improve the behaviours and attitudes towards disabled people however participants found personal and social identity were important considerations that can be positively impacted by the use of multifunction power wheelchairs.

Well-Living

The subjective experience of engaging in life was a major focus and outcome for all the participants and is often not fully measured by health professions. It is more than a state, such as "well-being" it is a practice/ praxis "well-living." This was introduced and defined in the study's findings (chapter 4) as "self-determined, satisfactory living". When mobility, environment and functionality are effectively addressed well-living can be achieved such as the experience of the participant at a concert with friends. The important role of leisure time was also found in a study of people with spinal cord injuries (Lee & McCormick, 2004). Well-living is the self- determined engagement in the overall occupation of living. It occurs when a person's expectations of their life within their environment and world are met. A person loses much of the world around them with restricted movement. With acquired disability the person is no longer able to construct the world in the complex, "multi-viewed" way possible with free body movement. Constricted body movement is not purely mechanical; it affects "body seeing" and "body intelligence" (Mattingly & Fleming, 1984, p.72). People's height can be half what it was because they are seated in a wheelchair; for example they become three feet tall instead of 6 feet tall. Multifunction power wheelchairs enable more body movement and participants reported an improved "view" of the world. It is important to find meaningful measures that reflect the outcomes self-determined and valued by individual users (Hammel et al, 2008). Expectations are different for different

individuals. People's constructions or interpretations of their world are individual as reflected in the participants' voices. Perhaps this is where a person centred criterion based measure such as the WhOM (Mortenson et al., 2007; Mortenson et al, 2008) can be more widely used than it is currently. The routine use of numerical satisfaction scales can assist with measuring the outcomes from a user's perspective.

Society in general uses technology and is allowed access to the activities that promote individually determined "well-living". So surely the question that should be asked is how society can increase access and choice for wheelchair users to modern technology that can promote greater health and participation in line with a primary healthcare philosophy (Ministry of Health, 2001; Tse, Penman & Simms, 2003; Tse, Wilson, Wright St Clair & Ford, 2003). The participants' voices presented in this research are compelling evidence for multifunction power wheelchair use.

Smoother more comfortable, stable, longer rides were experienced with the higher specification multifunction power wheelchairs. The different functions enabled greater participation for example at profound moments like 'standing up' (elevating the seat high low function) for the prayer "Lest We Forget" at the RSA (Returned Servicemen's Association) or being able to participate at church. Also reported was increased participation in work and community settings for example enjoying concert going, shopping, and accessing the natural outdoors. This lead to greater interaction with others and built relationships and memorable experiences. Participants just wanted to get on and live their lives and to a greater extent the multifunction power wheelchairs helped achieve this. A high level of satisfaction was expressed. This is consistent with comments from power wheelchair users in other studies (May & Rugg, 2010; McMillan & Soderberg, 2002). Independence, freedom of movement (enabled through the power functions), access, improved identity and occupational engagement are encapsulated in the meaning of well-living.

Study Limitations and Implications for Future Research.

The findings of this research must be kept within the context of its limitations. Firstly it is a small exploratory descriptive study with only 10 participants. With such a small convenience sample important perspectives could have been missed. Although the participants had a range of ages,

diagnoses and social backgrounds unfortunately no Maori (indigenous people of New Zealand) participants volunteered to participate. Maori are more highly represented in health and disability statistics (Ministry of Health, 2012; Robson & Harris, 2007) and it is important inclusive research is completed in the future. However, this study was a representational group in terms of a range of backgrounds, ages and impairments, with some consensus. It was also conducted in an urban centre and there were no rural based participants. In addition, the convenience sampling recruitment strategy naturally included adults who had already thought about their power wheelchair use and wanted to share their ideas. However no single research voice will ever provide all the answers as qualitative research is a discussion that needs to be on-going (Geertz, 1973). This study can be replicated and added to as it is hoped that sufficient detail has been provided in the methodology and appendices.

Other indications for research are retrospective studies and audits to look at the use and distribution of powered mobility to date which would assist with planning provision in the future Prospective longitudinal studies and case studies would provide more useful information in terms of describing how things have become easier or more difficult for users and how changes were managed overtime. Participatory action research could be used within services with users and therapists and other stakeholders in an effort to help users gain a stronger voice (French & Swain, 1997; Winter, 2006), increase awareness and promote on-going quality development in practice. This could include focus groups involving all stakeholders as a useful and productive way to discuss and brainstorm about some of the issues raised especially knowledge and self-advocacy, funding and provision, trials, repairs, backups and environmental design.

Discussion Summary

This chapter has discussed the rich findings from the interviews of ten adult users of multifunction power wheelchairs in relation to their experiences and perspectives. It confirms the challenges that other researchers have found and the fact that these challenges are on-going in New Zealand with on-going action required incorporating the principles of the Disability Strategy (2001). Person centred practice that incorporates person centred outcome measures and increased collaboration. User empowerment through transparent debate including the use of public funding for access to technology, and inclusive environments are essential. Issues such as repairability, affordability and future proofing solutions, including increasing the number of backup power

wheelchairs available need to be addressed. The value of multifunction power wheelchairs cannot be ignored because of the potential for increased independence and participation physically and socially to achieve 'well-living.' I close this discussion with the words of one participant which captures the great difference their multifunction power wheelchair has made to their life and their recommendation for the same outcomes for others:

> *The amount of independence and freedom I've felt from having this chair I'd want others to have as well, to also experience that… (7-54)*

The last chapter of this thesis draws the overall conclusions of the study.

Chapter 6: Conclusion

This qualitative descriptive study brings together the voices of ten users of multifunction power wheelchairs and explores their perspectives and experiences. The findings show that individuals with a range of severe physical impairments can benefit greatly from multifunction power wheelchair use. This is a newer group of high need users who are now able to participate in the community because of technology developments in power wheelchairs. Therefore the opportunity exists to significantly improve the lives of these users. The criterion for the provision of multifunction power wheelchairs needs to be both broad and generous. Thus this study supports this assertion because of the well documented benefits and potential they offer individuals for increased well- living.

A person centred approach to outcome measures is important. This is because multifunction power wheelchairs can enable users to have greater autonomy and control over their own lives as has been revealed in the study findings. Occupational therapists purport to be person centred, however when working with people there is always the tension between the complex reality of clients' lives and the systems, including funding processes as has been shown in this study. When assessing wheelchair and seating needs therapists need to heed the 'voice' of users as allegiance is to the clients. Services are there to serve the client, rather than the other powers within the system. For example, the literature indicates that recline and high-low seat functions are of benefit in a range of situations for users, so these functions need to be issued more often.

Many positive outcomes have been expressed by users and the challenges have been clearly articulated and need to be noted by all stakeholders. One important message is the demand for enhanced person centred practice, challenging practice norms, and a closer independent appraisal of new equipment and technology to improve affordability, reliability and design.

In addition, the findings suggest that inclusion of user groups in services is necessary to ensure users have an on-going voice to highlight the major issues and enhance their rights. Most importantly for occupational therapists, they are there to help address occupational challenges as they appear, including beyond the time of initial provision.

Further research and information is needed about multifunction power wheelchair intervention and outcomes that include: usage, training, reduction of environmental barriers and access to convenient transportation. This is because this user group has a higher level of disability and the environment is not fully inclusive. These people are the risk takers exploring new possibilities and breaking down stereotypical attitudes towards disability. Therefore their voices are important to support attitudinal and legislative changes. Further research is also needed about Maori use of this technology and they were not represented in this study group.

A key potential outcome of this study is contributing this knowledge to best practice guidelines for users to aid their decision making, and for occupational therapists to reference when assessing people for powered wheelchairs. This would include the considerations for certain activities such as using lifts or undertaking transport using the powered wheelchair, as well as justifications for recommending power functions for power wheelchairs and the consequences for not having these functions.

Lastly, this study goes some way to capturing the voice of people who represent users of power wheelchairs, whose lives may be either enhanced or limited by the type of mobility solution provided and the environment they live in. It is essential this voice becomes dominant rather than secondary to therapists' assessments and the opinions of other stakeholders. The evidence from the users in this study and in the literature provided a strong indication of the considerable difference multifunction power wheelchairs can make to people's lives. Therefore the autonomy to take up the challenge of "well-living" is something that reflects the aspirations of all individuals, because of their humanity, their spirit, whatever their ability, to be a part of their whanau (family) and wider communities. The outcome is reflected in the words of a Maori proverb: Te Ihi, Te Mana, Te Matauranga (translation: "Beyond what I imagined I could be").

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Appendices:

Appendix 1: Wheelchair Service Spreadsheet of 100 Discharged Client Files

Person's Medical Diagnosis	Decade of birth	Type/brand of wheelchair	Seat	Backrest
1. SB	1960	ULW	waffle	upholstery
2. MND	1960	**MWD***		
3. CP	1980	manualTNS	custom	custom
4. CP	1980	transit	custom	custom
5. Polio, OA	1920	MWD,hilo,elev legs (2010)		
6. CVA	1920	MWD, TNS	Std foam	Std foam
7. CP,deaf	1960	MWD,TNS	Std foam	Std foam,gel
8. CP	1950	MWD	custom	custom
9. CVA	1940	manual TNS	Std foam	custom
10. MS,CF	1940	MWD,TNS,elev,hilo (2009-10)	Std air	Matrix
11. CVA, dementia	1920	manual TNS	Std foam	Std air
12. CP, epilepsy	1970	manual TNS	custom	custom
13. Post-polio	1950	ULW	custom	custom
14. MS, MH, diabetes	1960	manual TNS	Std foam	Std foam
15. MND	1960	MWD,TNS	Roho	Vtrak
16. MND	1950	MWD,TNS	Roho	Vtrak
17. CP	1960	manual	Std foam	Std foam
18. CP	1990	manual TNS	custom	custom
19. MS (diagnosed 2011)	1960	**MWD,tilt***	Std air	Std foam
20. neuromuscular	1960	RWD	Std foam	Std foam
21. CVA	1930	manual TNS	Std foam	Std foam
22. Developmental Delay	1960	manual TNS	Std foam	Std foam
23. neuromuscular	1960	MPW (2011)	custom	custom
24. DMD,OP,OA	1980	**MWD,TNS***	Std foam	Std foam
25. SB	1970	ULW	Std air	
26. SB	1980	ULW	Std foam	
27. CP	1980	transit	Std foam	Std foam
28. SB	1960	ULW	Std air	Std foam
29. MS	1940	MWD,TNS, hilo (2011)		
30. CP,LD	1950	manual TNS	Std gel	Std foam
31. MS	1950	ULW		
32. DMD	1990	MWD,TNS,reclin (2011)	custom	Custom
33. CVA	1960	**MWD***	Std air	Std foam
34. SB	1990	ULW		
35. MS, peg	1930	MWD,TNS, stand (2011)		Std
36. T3 paraplegia, colostomy	1940	**MWD,TNS***	Std air	Std foam
37. MS	1960	MWD,TNS,hilo(2011)	Std foam	Std foam

Person's Medical Diagnosis	Decade of birth	Type of wheelchair	Seat	Backrest
38. CP	2000	manualTNS	modular	modular
39. MS (diagnosed 2001)	1960	**MWD,TNS***	Std foam	Std foam
40. Myotubular myopathy, spinal surg.	1990	MWD, TNS, recline(2011)	modular	modular
41. CP, Developmental Delay	1970	manual TNS		
42. CP athetosis	1950	MWD,TNS	custom	custom
43. DMD	1990	MWD	Std foam	Std foam
44. SB	1960	ULW		
45. MS	1940	power RWD TNS	Std air	custom
46. CP	1990	manualTNS	custom	Custom
47. MS	1950	MWD, TNS, hilo (2011)	Std air	Std foam
48. Paralysis, AKA(L),medical	1930	MWD,TNS	Std air	Std foam
49. DMD	1990	MWD,TNS,recline(2011)	Std foam	
50. CVA,diabetes,OA	adult	MWD,TNS	waffle	
51. Becker MD	1970	ULW, power wheels	Std air	
52. MND	1950	transit manual		
53. CP	2000	manual	modular	modular
54. Developmental Delay	1990	manual TNS	custom	custom
55. CP, Marfans syndrome	1970	RWD,TNS	Std foam	Std foam
56. C4 tetraplegia	1950	MWD	basic	basic
57. CP	1950	MWD,TNS	custom	custom
58. SB, neuro		MWD,TNS		
59. CP, MD	1960	ULW manual		
60. CP, epilepsy	1964	TNS manual	custom	custom
61. CP	1990	TNS manual	custom	custom
62. SCI	1990	MWD, tilt, high low	custom	custom
63. SB	1960	ULW	custom	custom
64. MND	1930	Power, TNS	Std air	Std foam
65. arthrogyposis	1980	ULW	upholstery	upholstery
66. T12, angioma	1940	ULW	Std foam	Std foam
67. meningitis	2000	ULW	custom	
68. SB	1990	ULW	Std air	
69. CP	1990	transit	custom	
70. Huntingtons	1960	manual TNS	Std foam	Std foam
71. CP	1960	MWD, TNS	Std foam	Std foam
72. SB	1990	ULW		
73. NM	1970	manual TNS	Std air	Std foam
74. Charcott Marie Tooth	1960	MWD	Std air	Std foam
75. Developmental delay	2010	buggy	modular	
76. CF Syndrome	1970	MWD, tilt	Std air	Std foam

77. Developmental delay	2010	buggy	modular	modular
78. Dementia	1920	TNS manual	Std foam	Std foam
79. Developmental delay	2000	TNS manual	custom	
80. Developmental delay	2010	Buggy	modular	modular
81. Developmental delay	2000	TNS manual	modular	modular
82. CVA	1920	MWD, TNS	Std foam	Std foam
83. Developmental delay	2000	TNS manual	custom	
84. CVA	1950	RWD	upholstery	upholstery
85. MS	1960	manual	Electric air	upholstery
86. Developmental delay	1990	manual	Std foam	Std foam
87. CP	1990	MPW	custom	custom
88. Developmental delay	2010	buggy	modular	modular
89. MS	1970	manual	Std air	Std foam
90. SB	1990	ULW	Std air	
91. Developmental delay	2010	buggy	modular	modular
92. DMD	1990	MPW	Std air	custom
93. CP	2000	TNS manual	custom	
94. Fredericks ataxia	1950	MWD, TNS	Std foam	Std foam
95. CVA	1940	manual,TNS,recline,elev	Std foam	Std foam
96. C4 incomplete tetraplegia	1940	MWD, TNS	Std gel	modular
97. CP	2000	MWD	modular	Std foam
98. MND, cognitive impairment	1960	TNS manual	Std air	Std foam
99. neuromuscular	1940	TNS manual	Std foam	Std foam
100. CVA	1940	RWD	Std gel	Upholstery

People who received/upgraded to multifunction power wheelchairs: N=13
***People identified as <u>possibly</u> benefitting from extra functions (from viewing notes only for example on-going discomfort not resolved by seating changes) that currently just have one function: N= 6.**

<u>Wheelchair and Seating Abbreviations:</u>
MWD: mid wheel drive power
RWD: rear wheel drive power
MPW: multifunction power wheelchair
ULW: ultra-lightweight self propelling
TNS: tilt in space
Recline: reclining back
Hilo: seat elevate or high low
Elev legs: elevating leg rests
Std: standard, off the shelf seating

Appendix 2: The Voices of Wheelchair Users within Studies 1990- 2012

Study Type	Study Authors	Year	N	Key Messages
I	Barker, Reid & Cott.	2004	10	Levels of acceptance, increased mobility, social, role loss, consider pre-stroke life style & values.
FG/DM	Batavia, Guy& Hammer.	1990	13	Device effectiveness is a priority with 16 additional evaluative factors.
Q	Belcher, Frank.	2004	268	Safety issues, adequate vehicle restraints required
I	Boss & Finlayson.	2006	7	Recognising the need, deciding, obtaining & using PW, affected by resources & communication.
CSS	Brandt, Iwarsson & Stahle.	2004	111	Increase in independence & participation; problems with environment and transport.
QS/I	Buning, Angelo & Schmeler.	2000	8	Transition to PW increased autonomy and self-sufficiency.
CoS	Chaves., et al.	2004	70	Accessible environment needs to considered with PW provision.
FG/I	Copolillo.	2001	9	Mobility device acceptance, usage and anticipating the future.
CoS	Davies, De Sonza, & Frank.	2003	64	Increased mobility and QOL, reduction of pain and discomfort.
I	Dewey, Rice-Oxley, & Dean.	2004	23	Tilt in space increased comfort, support, stability, sitting time and reduced pressure.
QS/I	Evans, Frank, Neophytou & De Souza.	2007	17	PW useful but outdoors, safety issues, waiting for delivery and housing modifications are barriers.
CoS	Edwards & McCluskey.	2010	202	PW have many benefits but accidents (21%) and access issues experienced
CoS	Frank, Ward, Orwell, McCullagh & Belcher.	2000	174	17 mishaps, PM component failure (39%), new activities undertaken (50%), need for follow-up.

MM/FG	Geisbrecht., et.al.	2011	8	Power assist wheels did not replace PW device.
I	Green., et.al.	2005	8	Experience of stigma is complex and socio-cultural context is important.
FG	Hedberg-Kristensson, Ivanoff &Iwarsson.	2000	22	More client-centred approach needed.
	Jedeloo, DeWitte &Schrijvers.	2002	67	Mobility devices create high satisfaction in users, routine follow-up needed.
survey	Kettle, Rowley & Chamberlain…	1992	3082	Comfort, suitability, environment were considerations.
I	May & Rugg.	2010	20	PW improved occupational performance but environmental constraints.
I	McMillen & Soderberg	2002	15	PW devices in general better QOL, fear of injury, acceptance and access problems, worry about future.
CV	Mills, et.al.	2004	20	Development of functional evaluation in wheelchair assessment.
I	Mortenson, Miller., et al.	2005	18	Meaning of PW (road rules) safety solutions in residential care.
I	Neri & Kroll.	2003	30	Negative consequences of barriers to health care: social, psychological, physical, economic and independence.
I, O, E, Ph	Papadimitriou.	2008	30	Becoming en-wheeled: making it part of one's living: re-embodiment.
Q, IPPA, WHODASII	Pettersson, Tornquist & Ahlstrom.	2006	32	PW essential, positive effects on leisure activities and participation.
I	Reid, Angus; McKeever & Miller.	2003	11	Lived space restriction, autonomy, advocacy to secure better housing and PW gave freedom.
FG	Ripat & Booth.	2005	6	AT user is unique, identify user priorities, current and future abilities and needs.
Q, RNLI	Rousseau-Harrison., et al.	2009	42	Social participation improved with PW and/or MW.

I, VAS	Samuelsson, Larsson; Thyberg & Gerdle.	2001	38	Individual seating adjustments decrease back pain and discomfort.
CS	Samuelsson, Larsson & Thyberg.	1999	1	Client priorities important.
FG	Scherer.	1996	700	AT dissatisfaction and abandonment needs to be considered, providers/users need to share knowledge.
CoS	Scherer., et al.	2005	150	Matching AT to user's needs for quality outcomes.
I	Titus & Polgar.	2012	?	Daily use of tilt function.
I	Verbrugge, Rennart & Madans.	1997	9526	AT is more efficacious than personal assistance.
Q	Ward., et al.	2010	32	High use of all MPW functions and satisfaction.
Q	Weiss-Lambrou, Tremblay, LeBlanc, Lacoste & Dansereau.	1999	24	User opinion and satisfaction is important.
Q	Wessle & Samuelsson.	2004	208	69% no follow-up; satisfied with AT but not service.
O,E	Winance.	2006	4	Matching the equipment to the person = embodiment.

Abbreviations:
AT: assistive technology; CoS: cohort study; CS: case study; CSS: cross-sectional; CV: cross validation; DM: Delphi method; E: ethnographic study; FG: focus group; I: interview; IPPA: Individually Prioritized Problem assessment; L: longitudinal; MM: mixed method; MW: manual wheelchair; O: observation; Ph: phenomenology; P: prospective; PW: power wheelchair; MPW: multifunction power wheelchair; Q: questionaire; QS: quantitative study; RNLI: Reintegration to Normal Living Index; VAS: visual analogue scale; WHODAS II: World health Organisation Disability Assessment ScheduleII

Appendix 3: Ethics Approval

Health and Disability Ethics Committees

2 November 2010

Northern X Regional Ethics Committee
Ministry of Health
3rd Floor, Unisys Building
650 Great South Road, Penrose
Private Bag 92 522
Wellesley Street, Auckland
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Ms Maria Whitcombe-Shingler
Mobility Solutions
Rehab Plus
P.O. Box 44037
Pt Chevalier, Auckland

Dear Maria

Re: Ethics ref: **NTX/10/EXP/213** (please quote in all correspondence)
Study title: Adult perspectives and experiences of using multifunction power wheelchairs in Aotearoa, New Zealand
Investigators: Ms Maria Whitcombe-Shingler
Supervisor: Sian Griffiths

Thank you for your application received 2 November 2010. The above study has been given ethical approval by the Chairperson of the **Northern X Regional** Ethics Committee under delegated authority.

Approved Documents

- Protocol number [undated, received 1/11/11]
- Advertisement [undated, received 1/1/11]
- Information Sheet/Consent Form – **please print on organisation's letterhead and insert version number and date as footer**

This approval is valid until 2 November 2011.

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Annual Progress Reports and Final Reports

Should you wish to extend your study, a Progress Report is due to the Committee by **2 November 2011.** If the study is completed before due date, please forward an end of study report. The Annual/Final Report Form that should be used is available at *www.ethicscommittees.health.govt.nz.*

Appendix 4: Semi Structured Interview Guidelines and Questions:

Introduction: My name is Maria; I am an occupational therapy research student interested in people's experiences and perspectives of multifunction power wheelchair use.
As someone who has been using a multifunction power chair for some time you are in an expert position to share your experiences.
The information collected will be confidential and it will be used to increase the understanding of multifunction power wheelchair use in New Zealand. You will receive a copy of the summarized research findings at the end of the study. The information from up to 10 interviews will be combined in a report and nothing you will say will be identified with you personally.
As we go through the interview if there are any questions please feel free to ask. Or if there is anything you don't want to answer just say so. I would like to record what you say so I don't miss any of it. I don't want to take the chance of relying on my notes and maybe missing something that you say or inadvertently changing your words somehow. So if you agree, I'd very much like to use the recorder. If at any time during the interview you would like the recorder turned off just let me know.
Thank you so much for agreeing to be interviewed. I have some general trigger questions developed from the literature I have read but please feel free to use your own ideas.

GENERAL:

Could you explain the nature of your disability and the background to how you came to get a multifunction power wheelchair?

How would you describe your multifunction power chair? What comes to mind when you think about your power chair? What **functions** do you have on it?
Tell me how your life has **changed** since using the multifunction power wheelchair? What **impact** has the power chair had on you, your life and level of **independence**?
What is a **typical day** like in your power chair?
Overall how well does your power chair suit your **lifestyle, roles and responsibilities**? How well does the power chair meet your **needs**?

OCCUPATIONAL PERFORMANCE:

(It may be helpful to think about having a wheelchair without the various additional features to comment on the difference).

How does the power chair affect your ability/ enable you and/or your caregivers to perform **self care** activities?
How does the power chair affect your ability to rest and to **relax**?
How does the power chair affect your **interests, hobbies and work**?
How does the power chair affect your ability to **interact** with others?
How has the power chair impacted on your **roles** and **relationships** with others?
What sort of **assistance** do you have with the use of the power chair?
How does your power chair impact on you getting out into the **community**?
What is it like to **transport** your power chair?
How well does the power chair suit your **home environment**?

POSITIVES:

Tell me how do you view your power chair overall? How do you feel about your power chair?
How **satisfied** are you? What are the positive things about using your power chair? What

functions do you like to use the most, singly or in combination and why? TILT IN SPACE SEAT, ELEVATING (High/low) SEAT, RECLINING BACK, STANDING FUNCTION, ELEVATING LEGRESTS and ATTENDANT CONTROL.
Would you recommend your power chair to other users and why?

NEGATIVES:
Tell me about the negative things about using your power chair? What would you change or improve about the power chair? What sorts of **problems** have you had with the power chair? What are the **maintenance, adjustment or repair** issues? Are there any **safety** issues?

CONCLUDING:
Have you got any final comments you would like to make? Is there anything else that I could have asked you? Any further thoughts you might have, will be very welcome. If you think of something later please feel free to contact me.

THANKYOU:
Thank you so much for participating. If it is OK with you I would like you to check the written transcription of the interview when I have completed it. I will return it to you and give you ten days to let me know if there are any changes to it you want to make. If I don't hear back from you after those ten days I will assume you are happy with the interview that you did with me.

Appendix 5: Advertisement for Participants

MULTIFUNCTION POWER WHEELCHAIR USE

ARE YOU INTERESTED IN SHARING YOUR EXPERIENCES OF USING A MULTIFUNCTION POWER WHEELCHAIR?
DO YOU USE A POWER WHEELCHAIR ON A DAILY BASIS THAT HAS MORE THAN ONE POWER FUNCTION INCLUDING TWO OR MORE OF THE FOLLOWING?

- **TILT IN SPACE SEAT,**
- **ELEVATING SEAT,**
- **RECLINING BACK,**
- **STANDING FUNCTION,**
- **ELEVATING LEGRESTS**

BE PART OF A STUDY THAT LOOKS AT ADULT PERSPECTIVES AND EXPERIENCES OF USING MULTIFUNCTION POWER WHEELCHAIRS IN AOTEAROA, NEW ZEALAND.

Maria Whitcombe-Shingler, an occupational therapist and Masters Candidate at Otago Polytechnic, would like to invite adults to be part of this study to discuss their perspectives and experiences of using a multifunction wheelchair in the Auckland region.
The aim of the study is to give users an opportunity to share their experiences confidentially. It involves being personally interviewed for 45 minutes in your home or quiet place of your choosing.
If you are interested please contact Maria Whitcombe-Shingler on 027 651 9318
or email Maria at **mariaWS@adhb.govt.nz**
or mail Attention Maria Whitcombe-Shingler, PO Box 44037, Pt Chevalier, Auckland 1002

This study has received ethical approval from the Northern X Regional Ethics Committee, which reviews northern regional studies.
Ethics Reference: **NTX/10/EXP/213**

Appendix 6: Participant Information Letter and Consent Form

Dear Participant,

Thank you for your interest in participating in a study about your experiences of using a multifunction power wheelchair. This is for a project entitled "Adult perspectives and experiences of using multifunction power wheelchairs in Aotearoa, New Zealand."

What this will involve?

If you consent I would like to interview you about your experiences of using your multifunction power wheelchair. It will be confidential and I can come and visit you at your home or another quiet place of your choosing. You can have someone present with you for example a family or whanau member. The interview will take approximately 45 minutes. The interview will need to be recorded but once it has been written down and checked with you the audio recording will be destroyed.

The kinds of things I will ask you about are to describe what it is like to use your multifunction power wheelchair in your everyday life, in what ways is the chair helpful? And is there anything you would change about your chair? The information recorded will be anonymous, there will be no identifying information and you can choose an alternative name or pseudonym. The information will be analysed for common topics or themes along with information from another up to 9 interviews and then it will be published.

The study is low risk but if you have any queries or concerns regarding your rights as a participant in this research study you may wish to contact an independent Health and Disability Advocate. This is a free service provided under the Health and Disability Commissioner Act.
Free phone: 0800555050
Free fax: 0800 27877678 (0800 2 SUPPORT)
Email: advocate@hdc.org.nz

What are the benefits of the study?

The study will provide feedback from users about their use of multifunction power wheelchairs. This will encourage a greater understanding by everyone involved including other users, therapists and people involved with funding.

More information about the study can be found by contacting:
Maria Whitcombe-Shingler

Mobile: 027 651 9318 Email: **mariaWS@adhb.govt.nz**
Mail: Attention Maria Whitcombe-Shingler, PO Box 44037, Pt Chevalier, 1002

This study has received ethical approval from the Northern X Regional Ethics Committee, which reviews northern regional studies.
Ethics Reference: NTX/10/EXP/213

CONSENT FORM

Study title: Adult perspectives and experiences of using multifunction power wheelchairs in Aotearoa, New Zealand. Ethics reference: NTX/10/EXP/213

I have read and I understand the information sheet for participants taking part in a study designed to investigate adult perspectives and experiences of using multifunction power wheelchairs in Aotearoa, New Zealand. YES/NO

I have had the opportunity to discuss the study and I am satisfied with the answers I have been given. YES/NO

I have had the opportunity to use family/whanau support or a friend to help me ask questions and understand the purpose and process of the study.
YES/NO

I confirm that I have had the opportunity to request an interpreter. YES/NO

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time, and this will in no way affect my healthcare now, or in the future. YES/NO

I have had this study explained to me by Maria Whitcombe- Shingler and I can make contact if I have any questions about the study at any time.
YES/NO

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
I choose a pseudonym……
I consent to my interview being audio taped. YES/NO

I consent to take part in this study. YES/NO

Participant Signature…….Date……

Researcher signature…… Date……
Maria Whitcombe-Shingler

Appendix 7: Interview Transcript Example

Interview Two

Describe the chair you have?
I always have to look down here. It is a Quantum 6000.

What functions does it have?
It has a tilt function and high low and anterior tilt function
And that is probably that

Does it have a reclining back as well?

The seat tilts

The high-low and tilt

So when you think about your chair what comes to mind? What do you think about it?

Um, it has been quite good I am not 100 percent sure when I got it I must have had it at least a year, the one thing that is very negative with it is that it is very heavy and I only just recently found out because downstairs they have roll on roll off scales and it weighs 186 kg and I was originally told it weighed 140 kg so that creates a lot of problems with transporting it and it is too heavy to fit on the hoist at the moment on my vehicle so that is probably the thing I don't feel happy about is the weight but apart from that in terms of its function it is very good, it is great actually

How has your life changed since you got this chair?

It has been really good we have two young children and they are very sporty and athletic and like to be outside doing things and with this chair we can do a lot more around the neighbourhood where we live and getting to their school is down a steep pathway, quite a steep pathway and this chair handles it with ease whereas the other chair was touch and go and if it was raining I would be a bit nervous about it, it didn't have all its wheels on the ground and so this one is a lot more powerful and the battery seems to last well yeah, it is really good, the only negative is the weight and if you get off the path and onto a bit of grass you have to be careful as you can easily get stuck

Do you live in a semi rural environment?

Well no we don't but there are some of these bush walks, we can go through this gully and right around the village, and there are lots of walking tracks and things and we have got to make the most of those

Appendix 8: Example of Stage Two Data Analysis.

Interview One Transcription *(*Analysis in brackets*)*

Can you describe your type of chair please?

Magic Mobility Frontier, it is an absolutely awesome chair, I hadn't seen anything like this before this, this is my second power chair, my rotator cuffs stopped working because I just get out and do what I want to do, so to save shoulders got power (active participation, protect from injury)

first power chair was Invacare chair, I had manual for 4 or 5 years

I had an Invacare one and at the time I didn't have a clue what was out there, if I had known then (knowledge is power)

and I was given choices I would have got this and I wouldn't have needed all the stuff of the other one (informed choice),

I think this chair meets everybody's needs (flexible, adaptable)

And it is so much cheaper in price compared to Invacare ones and Allied Medical, their cheapest ones start off at $30,000 and this one starts off at a third of the price. Base price is cheaper (cost effective).

All terrain. Wheels interchangeable, I keep all terrain wheels on, a lot more stable with these wheels on. (Stability, safety).

I have worked with people with disabilities and they are so scared of a power chair and a little bit of a slope you can see people are frighten and tense up. This chair is so stable and sits lovely and I think it is a chair that should be looked at more for people. (Reduced fear, increased confidence).

To be honest I have not seen a Frontier used in this way in an indoor work environment.

Invacare do a RAM, but motors not upgraded

This one has larger motors to take the strain of the larger wheels. (Power*).*

It is just a more purpose built chair.

Custom box put on where the legs were. (Customisation).

Goes up/down, reclines, tilt, lights…visibility is not so good at night when I go out so it is good to have the lights, the actual price with all additional features is around the same as other chairs, I couldn't believe the prices, I went to a Show Your Ability show, after I found them on the net and contacted them and found out about the show. Frontier comes from Australia, there is a total 4 wheel drive too (*lights for safety, night time visibility, equipment show useful for knowledge).*

How has your life changed?

A lot more relaxed when you are out. (Reduced physical strain).

So nice, no worries when I go out (Reduced mental strain).

There are still limitations but a lot less limitations (Reduced limitations).

A lot more stable that is the big thing. (Stability important).

Have you tipped out a lot in the past?

I haven't but you could easily, the others are so narrow, I tried one before I realized that these were out there, terrible horrendous, so narrow, just complicated compared to this, very simple design. (Importance of good design).

Appendix 9: Example of Stage Three Data Analysis.

FUNCTIONS statements (interview# - phrase line #)

General Functions

- *4 x4 chair goes up, down, reclines, tilts, lights….visibility is not so good at night when I go out so it is good to have the lights, the actual price with all additional features is around the same as other chairs, I couldn't believe the prices, I went to an equipment show, after I found them on the net and contacted them and found out all about them (1-5).*
- *It [chair] has a tilt function and high low and anterior tilt function (2-1)*
- *It [chair] had to be midwheeldrive and high enough for me to get off, it needed to be light enough to go on the hoist and ….anyway I looked at lots of chairs and they were either too big like the other company's one, this chair wasn't such a monster, it was so huge and so long and the high low didn't go high enough so I couldn't get off it because I am quite tall and if my legs are straight I can't get off it…….(2-40)*
- *It is brilliant, it is my legs, it suits all my purposes, it tilts backwards and forwards, um, it lifts up quite high so if I need to get into a high cupboard I can, everything is comfortable on it, the back, the headrest (9-3a).*
- *I use the tilt, recline, and the leg elevate the most, when you go down the footpath, ramp, shop thresholds you have to have the legs high-up. I also use leg elevate to change leg positions and manage the swelling. The leg elevate makes a big difference (9-23)*
- *It has a lot of functionality with functions and getting around as well, it has high low, power recline, tilt and elevating leg rests (10.1)*

Stability

- *I knew what I wanted because I come from a mechanical background before my accident I worked with farming and machines so I understand all that a lot more than other people probably and I just wanted something stable that would allow me to go off the road abit more (1-9)*

Tilt

- *….because I have trouble with back pain and I can only sit in one position for short time so I have to change back and tilt because when working on computer OK but can't sit for long time, yes, tilt and recline mostly used (6-13).*
- *I use the tilt in space the most because I am use to that; I've used it for years' it depends how I feel, sometimes I just tilt back or move myself I don't always know why I do it but I'll just move myself (8-21,26).*
- *For pressure management, I honestly try to use the tilt; every half an hour for at least 10 to 15 minutes (9-13)*
- *Use tilt for relaxing sometimes (10.5)*
- *…probably use the chair tilt the most, to lean back on a hill (10-17)*