

EXPLORING THE IMPACT OF WHEELCHAIRS ON INDIVIDUALS IN RESIDENTIAL
CARE: A TWO-PHASE, MIXED-METHODS STUDY

by

WILLIAM BENNETT MORTENSON

B.Sc.O.T., The University of Alberta, 1991

M.Sc., The University of British Columbia, 2003

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

in

THE FACULTY OF GRADUATE STUDIES

(Rehabilitation Sciences)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

June 2009

© William Bennett Mortenson, 2009

Abstract

Wheelchairs are the primary means of mobility for most of the older adults living in residential care. Despite their intuitive benefits, little research has explored the outcomes of wheelchair use for facility residents. Therefore, a two-phase, mixed-methods project was undertaken.

Phase 1: Exploratory Ethnographic Study

Objectives

1. To explore the perceptions and experiences of facility life among residents who use wheelchairs as their primary means of mobility and to examine how wheelchairs are used in these settings.
2. To identify nondemographic factors that enable or curtail the mobility, participation and life satisfaction of these residents.

Method

Sixteen residents from two facilities took part in participant observations, and these residents or surrogate family members completed a series of in-depth interviews.

Results

We drew upon the work of Pierre Bourdieu to understand how wheelchairs and other forms of capital could either enable or curtail the things residents did and the places that they went. These findings emphasize the critical role that the facility environment plays in the lives of residents. This study identified a wide range of potential wheelchair-related, environmental, and personal factors related to resident's mobility, participation, and life satisfaction.

Phase 2: Quantitative Cross-sectional Study

Objective

To identify the predictors of mobility, participation and life satisfaction of residents who use wheelchairs as their primary means of mobility.

Method

We conducted a cross-sectional study with 268 residents from 11 facilities. To measure independent and dependent study variables we administered standardized personal, wheelchair-related and environmental tools and collected socio-demographic and wheelchair equipment data.

Results

Wheelchair skills (including the capacity to engage brakes and manoeuvre) were the most important independent predictors of mobility. Depression was the most important independent

predictor of life satisfaction among self-responding and proxy subjects and of participation for self-responding subjects. For proxy subjects, mobility was the most important independent predictor of participation; and depression approached significance.

Significance

The study findings emphasize the pivotal role that wheelchairs play in the lives of residents, reveal institutional practices that may curtail their mobility and participation, suggest potential policy and practice changes, and lay the groundwork for future research.

Table of Contents

Abstract	ii
Table of Contents.....	iv
List of Tables	vi
List of Figures.....	viii
Acknowledgements.....	ix
Dedication.....	x
Co-Authorship Statement.....	xi
Chapter 1: Introduction.....	1
References.....	15
Chapter 2: Grey Spaces: The Wheeled Fields of Residential Care	23
References.....	40
Chapter 3: Factors Related to Mobility, Participation and Quality of Life Among Individuals in Residential Care Who Use Wheelchairs as their Primary Means of Mobility. An Exploratory Qualitative Study	45
References.....	65
Chapter 4: Predictors of Mobility in Individuals in Residential Care	70
References.....	93
Chapter 5: Predictors of Participation and Life Satisfaction among Long-term Care Residents Who Use Wheelchairs as a Primary Means of Mobility	97
References.....	121
Chapter 6: Conclusion, Synthesis, and Recommendations for Future Research.....	127
References.....	140
Appendix 1 Explication of Bourdieu's Concepts of Habitus, Field and Capital.....	143
References.....	146
Appendix 2 Ethical Approvals.....	147
Appendix 3 Participant and Interview Guide Examples.....	154
Appendix 4 Member Checking Process.....	158
Appendix 5 Rationale for Tool Selection	161
References.....	169
Appendix 6 Description of Measures Included in the Study and Their Coding.....	171
References.....	210
Appendix 7 Test-Retest Intraclass Correlational Coefficients (ICCs) for Measures.....	212

Appendix 8 Missing Data Analysis	213
Appendix 9 Pearson Correlation Matrix of Independent and Dependent Variables for Total Sample.....	215
Appendix 10 Pearson Correlation Matrix of Independent and Dependent Variables for Self-responding Subjects	217
Appendix 11 Pearson Correlation Matrix of Independent and Dependent Variables for Proxy Subjects.....	219

List of Tables

Table 3.1 Differences and Similarities between Facilities Studied	57
Table 3.1 Mobility Factors, and Percentage of Documents in Which These Were Identified, and Examples.....	58
Table 3.2 Participation Factors, Percentage of Documents in Which These Were Identified, and Examples.....	60
Table 3.3 Quality of Life Factors, Percentage of Documents in Which These Were Identified, and Example.....	62
Table 4.1 Descriptive Facility Level Data	85
Table 4.2 D Descriptive Statistics and Mean Nursing Home Life Space Diameter Score (NHLSD) for Combined, Self-responding and Proxy Subject Groups.....	86
Table 4.3 NHLSD Regression Analysis for Total Sample (N=257)	89
Table 4.4 NHLSD Regression Analysis for Self-responding Sample (N=139)	90
Table 4.5 NHLSD Regression Analysis for Proxy Sample (N=110)	91
Table 5.1 Characteristics of Self-responding and Proxy Subjects.....	115
Table 5.2 Regression Analysis to Identify Factors Associated with Participation Frequency for Self-responding Subjects (N=143).....	117
Table.5.3 Regression Analysis to Identify Factors Associated with Participation Frequency for Proxy Subjects (N=116).....	118
Table 5.4 Regression Analysis to Identify Factors Associated with Life Satisfaction of Self-responding Subjects (N=146)	119
Table 5.5 Regression Analysis to Identify Factors Associated with Life Satisfaction of Proxy Subjects (N=110)	120
Table A5.1 Possible Tools to Measure Factors and Variables Identified in the Qualitative Phase of the Research.....	162
Table A6.1 Description of Measures Included in the Study and Their Coding.....	171
Table A7.1 Test-Retest Interclass Correlational Coefficients (ICCs) for Measures.....	212
Table A8.1 Missing Data Analysis	213
Table A9.1 Pearson Correlation Matrix of Independent and Dependent Variables for Total Sample.....	215
Table A10.1 Pearson Correlation Matrix of Independent and Dependent Variables for Self-responding Subjects	217

Table A11.1 Pearson Correlation Matrix of Independent and Dependent Variables for Proxy Subjects.....	219
--	-----

List of Figures

Figure 3.1 Modified Matching Person to Technology Model	64
Figure 4.1 Constructs Included in the Study Organized According to the Matching Person to Technology Model	92
Figure A4.1 Conceptual Diagram of Quality of Life for Residents	160

Acknowledgements

The Canadian Occupational Therapy Foundation and the British Columbia Network on Aging Research provided funding for the first phase of the research. The Canadian Institutes of Health Research (grant number 175794) provided funding for the second phase of the study.

Personal financial support was provided by the Canadian Occupational Therapy Foundation, the Michael Smith Foundation for Health Research (MSFHR) and the Canadian Institutes of Health Research (CIHR) via a Quality of Life Strategic Training Fellowship in Rehabilitation Research from the CIHR Musculoskeletal and Arthritis Institute and a Clinician Fellowship.

It is said that it takes a community to raise a child, and the same is true for me as a doctoral student. I want to thank Dr. Bill Miller, my thesis supervisor, for his unflagging support, encouragement, and guidance. I want to thank Drs. John Oliffe and Catherine Backman, as members of my thesis committee, for their ongoing support, keen insights, and helpful advice.

Several recently graduated Master of Occupational Therapy students helped bring this project to fruition including Sneha Shankar, Justin Wallace, Tamara Van Dyke, Brianne Vetter, Anna Rancourt, and Kerstin Crosthwaite. I would also like to thank all of the research assistants who worked diligently on this project, including Chris Stellar, Kristina Smith, Lyndsay Martin, Jennifer Lee, Tristan Thomas, Chanudi Weerasinghe, Sarah Hamilton, Victor Tang, Bobby Lee, Silvana Doria, and Barinder Chauhan. I need to extend my warmest appreciation for the indefatigable efforts of Elmira Chan who acted as study coordinator for the second phase of this research.

I also want to thank my fellow graduate students who shared this incredible journey with me including Amira Tawashy, Paula Rushton, Christina Ekegren, Kristin Konnyu, and Jocelyn Harris.

Finally, I would like to thank my family members for their long-distance encouragement, my wife Patricia for enabling me to complete this project and to attend conferences in glamorous locations, and my children for demanding that my life remained balanced.

Dedication

To:

All of the residents who gave their time and shared their lives with me, residential care facility staff who helped me so much along the way, and Patricia Mortenson who provided tireless and unwavering support throughout this process.

Co-Authorship Statement

Members of my thesis committee coauthored all of the data chapters of this thesis. In consultation with my committee members, I identified and developed this research program; carried out data collection; and analyzed the findings of the study. I was first author for all of the data chapters. My committee members provided ongoing feedback on drafts of these manuscripts.

Chapter 1: Introduction

Wheelchairs are one of the most important compensatory devices prescribed by rehabilitation practitioners (Mann, Llanes, Justiss, & Tomita, 2004). Despite their intuitive benefits, little research has explored the impact that they have, particularly for individuals living in residential care. Although the benefits of properly prescribed and fitted wheelchairs have been documented (Trefler Fitzgerald, Hobson, Bursick & Joseph, 2004), some studies have found that residents who use wheelchairs experience a variety of wheelchair-related problems, including seating discomfort (Fuchs & Gromak, 2003; Shaw & Taylor, 1991), pressure ulcers (Brienza, Karg, Geyer, Kelsey & Trefler, 2001) and reduced independent mobility (Simmons Schnelle, MacRae & Ouslander, 1995). Furthermore, wheelchairs sometimes are used as a means of restraining or controlling, rather than enabling, residents (Gubrium, 1975; Smithers, 1990); and the use of wheelchairs has been identified as a source of stigma (Cahill & Eggleston, 1995; Mortenson et al., 2005). To develop an understanding of the relationship between these outcomes, residents' experiences, and facility practices we conducted a two-phase, mixed-methods research project.

Definition of Terms

Assistive Technology

According to the United States Assistive Technology Act of 2004 (ATA, 2004), an assistive technology device is defined as “any item, piece of equipment, or product system, whether acquired commercially or off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities.”

Critical Ethnography

Critical ethnography differs from traditional ethnography as it is overtly political and is intended to address issues of oppression and social justice in a particular setting (Thomas, 1993).

Mobility

For the purpose of this thesis, mobility will refer to the movement of an individual from one place to another, either independently or with the assistance of others.

Participation

The International Classification of Functioning, Disability and Health, (ICF) defines participation simply as “involvement in a life situation” (World Health Organization, 2002a, p. 10). According to the ICF, participation is measured by determining an individual's performance (i.e., what he or she actually does) rather than his or her capacity (what he or she is capable of)

(World Health Organization, 2002b). Participation has been equated with the term “life habits” from the Disability Creation Process Model (Desrosiers, 2005), which are defined as “daily activities or social roles valued by the person or her/his socio-cultural context according to her/his characteristics (age, gender, socio-cultural identify, etc.)” (Fougeyrollas, Noreau, & Boschen, 2002, p. 8).

Physical Restraint

Physical restraints are defined as “any manual method or physical or mechanical device, material, or equipment attached or adjacent to the individual's body that the individual cannot remove easily, which restricts freedom of movement or normal access to one's body” (Health Care Financing Administration 1992, p. 76).

Residential Care Facility

Residential care facilities are known by about 20 different names that include adult care homes, assisted living facilities, long-term care facilities, and nursing homes (Mitchell & Kemp, 2000). Residential care facilities are places where individuals with a variety of cognitive, physical, and functional impairments live for extended periods, because of the nature of health care services that they require, which include nursing care and daily personal care.

Satisfaction with Life

Satisfaction with life is defined as “one’s assessment of the overall condition of one’s life, as derived from a comparison of one’s aspirations with one’s actual achievements” (Baum & Okun, 1983, p. 261). Satisfaction with life is sometimes used synonymously with quality of life, but the construct of life satisfaction precludes the use of objective comparisons that are part of some definitions of the latter construct.

Wheelchair

A wheelchair is a mobility device that is fundamentally a chair with wheels. Unless otherwise noted, the term “wheelchair” refers to both powered and manual devices (including “scooters”) and includes the wheelchair frame and seating components, such as the cushion and back.

Literature Review

- **Wheelchair use is common among those living in residential care.**

It is estimated that over half of the adults, 65 years of age and older, living in Canadian residential care facilities use a wheelchair as a means of mobility (Shields, 2004). The expected doubling of the number of people 65 or older over the next 25 years (Statistics Canada, 2005)

will likely lead to a dramatic rise in the number of people in residential care facilities and to a corresponding increase in the number of individuals who use wheelchairs in these settings.

- **Wheelchair use is a complex phenomenon.**

Wheelchairs can provide a variety of potential benefits, but there may be negative consequences associated with their use. Non-residential care facility specific research has indicated that wheelchairs provide a wide variety of benefits to users. Manual and power wheelchairs, for example, can enhance well-being by promoting comfort, increasing independent mobility, facilitating social interaction and enabling participation in desired activities (Brandt, Iwarsson & Stahle, 2004; Devitt, Chau & Jutai, 2003; Sapey, Stewart & Donaldson, 2005). Conversely, some studies have described the negative outcomes arising from improper use of wheelchairs. For example, wheelchairs may cause pressure sores (Brienza et al., 2001) and discomfort (Crane et al., 2004), may limit independent mobility, and may prevent involvement in desired leisure and community activities (Hoenig, Landerman, Shipp & George, 2003).

Because wheelchairs are both a part of the environment and a method of interacting with it, wheelchair-related issues extend beyond the wheelchair itself. Wheelchairs are not neutral objects for they can invoke negative reactions from wheelchair users and others (Cahill & Eggleston, 1995). Despite legislation to improve accessibility and to prevent discrimination, attitudinal and environmental barriers remain serious problems for many individuals who use wheelchairs (Meyers, Anderson, Miller, Shipp & Hoenig, 2002; Mortenson et al., 2005). This may explain, at least in part, the finding that some individuals have difficulty accepting a wheelchair (Barker, Reid & Cott, 2004; Bates, Spencer, Young, & Rintala, 1993). It may also be the reason why, in a study of 454 adults with and without chronic conditions, the perceived quality of life was lowest for individuals who used wheelchairs in comparison to individuals from a variety of other groups, including individuals with mobility impairments who did not use a wheelchair, nursing home residents, and individuals with acquired immune deficiency syndrome, terminal cancer, and stroke (Patrick, Kinne, Engelberg, & Pearlman, 2000). These studies indicate that wheelchair use represents an important and complex multi-dimensional phenomenon (Routhier, Vincent, Desrosiers & Nadeau, 2003) that is well suited for further exploration by using a mixed-methods approach.

Although little research has been conducted with residents, a number of personal and environmental variables that predict mobility in community dwelling adults and in wheelchair users have been identified. Some of these predictors include functional status (Baker, Bodner, &

Allman, 2003; Bendixen, Mann, & Tomita, 2005; Peel et al., 2005), depression (Baker et al., 2003; Peel et al., 2005), age (Peel et al., 2005), cognition (Peel et al., 2005), wheelchair fit and accessibility (Hoenig, Pieper, Zolkewitz, Schenkman, & Branch, 2002). Among residents, functional status and social participation has been moderately correlated with mobility (Tinetti & Ginter, 1990).

- **Despite the prevalence of wheelchairs in residential care facilities, research in this setting is limited.**

A literature search using the terms “long term care,” “residential care,” “nursing home*,” “power mobility,” and “wheelchair*” (where “*” indicates “wildcard”) in the electronic databases CINAHL, EMBASE, Pub-med and Sociological Abstracts from 1990 to the present was conducted to find empirical studies that explored wheelchair use in residential care facilities. After we excluded one article written in a language other than English, only 12 empirical, mobility-related studies relevant to this research were identified (indicated by *italics* in the next two sections), of which only six were published after 2000.

- **Residents experience a variety of wheelchair-related problems.**

Based on nationwide survey data, *Clarke, Chan, Santaguida, and Colantonio (2009)* found that over 50% of Canadian facility residents used a wheelchair. Although walking difficulties were strongly associated with wheelchair use in this sample, among those with high school education or higher, the association between walking difficulties and wheelchair use was significantly reduced.

Four studies examined the appropriateness of wheelchairs and wheelchair seating provided for residents of residential care facilities. *Shaw and Taylor (1991)* reported that 80% of wheelchair users had at least one of the following problems: discomfort, hindered mobility, or poor posture. These problem or problems were considered severe for 34% of residents. *Fuchs and Gromak (2003)* found that, for 21 of 42 residents, goals to change postural alignment, improve mobility, decrease risk for pressure ulcers or increase comfort were not met. In addition, for the 42 residents, 93 instances of inadequate wheelchair equipment were reported. *Simmons et al. (1995)* indicated that 46% of residents in their study had wheelchairs that were either dysfunctional or poorly fitted, which negatively affected wheelchair use. *Krasilovsky (1993)* found that 54% of residents required seating intervention to improve posture and alignment.

Four studies examined issues of independent propulsion and safety. *Brechtelsbauer and Louie (1999)* found that independent wheelchair mobility was minimal among 101 residents.

They concluded that the goal of independent mobility was not realistic for the majority of residents, but they did not make linkages between specific wheelchair factors (e.g., goodness of fit) and mobility. In terms of power mobility safety, *Reed, Yochum and Schloss (1993)* found that 57% of scooter users had received no driver training; and 30% of users felt that other drivers were unsafe. Our research revealed that residents might also be prevented from accessing power mobility, which in turn limits independent mobility (*Mortenson et al., 2005; 2006*). One participant in this research noted, after her power wheelchair had been removed due to safety concerns, “I hated it because you’re stuck everywhere. Because staff won’t push you. [...] I see a lot of people in manual chairs who can’t go anywhere. [Staff] just leave them by their beds.” This quote illustrates the interplay between independent mobility, wheelchair access, and staffing issues that requires further, in-depth study.

- **Institutional factors, which include 1) availability of equipment and prescription services, 2) the physical environment, and 3) institutional policies and practices, have a strong influence on wheelchair use in residential care facilities.**

In terms of the availability of wheelchair equipment and wheelchair prescription services, a recent intervention study indicated that, with the availability of properly trained prescribers, wheelchairs could improve independent mobility and health-related physical activity and social function (*Trefler et al., 2004*). *Bourbonniere et al. (2007)* found that, in two facilities with good access to these resources, the need for wheelchair seating intervention was substantially lower than in other facilities (described in unpublished research findings from Forward & Miller, 2000). As well, over half the residents in these two facilities were independently mobile, which was in sharp contrast to the findings of *Brechtelsbauer and Louie (1999)* that included a similar sample of residents.

In terms of the physical environment, our research (*Mortenson et al., 2005*) suggested that facility environments are poorly suited for wheelchair mobility. For example, participants indicated that the hallways were narrow and frequently cluttered with equipment, which often prevented residents from getting where they wanted to go and increased the likelihood of injuries. *Cutler et al. (2006)* found that only 9% of facilities surveyed were free of clutter, including linen carts and waste containers.

In terms of institutional policies and practices, *Smithers' (1990)* ethnography of wheelchair use in one facility found that there was a “dark side” to wheelchair use, as they were sometimes employed to restrain residents, rather than enable their participation. For example,

wheelchairs were sometimes used to control residents by deploying brakes that residents could not release independently or by using restraints to prevent residents from transferring independently out of their chairs.

Although the findings of Smithers' study are provocative, it was conducted over 15 years ago; and many facilities in Canada have now adopted a policy of least restraint (Flaherty, 2004). My clinical observations and those of others (Dimant, 2003) suggest, however, that the use of restraints continues in the form of wheelchair "positioning devices," such as seatbelts, wheelchair brakes and tilt-in-space wheelchairs, which are sometimes used to prevent independent mobility and transfers. These findings show that understanding the role of institutional factors is critical to improving wheelchair use among residents.

- **Wheelchairs have been identified as sources of stigma.**

Some research has suggested that wheelchair use may represent a source of what Goffman (1963) described as stigma (Cahill & Eggleston, 1995). Goffman defined stigma as "bodily signs [that] expose something unusual and bad about the moral status of the signifier" (p. 1). He noted that an individual who is stigmatized "is thus reduced in our minds from a whole and usual person to a tainted, discounted one" (p. 3). In this regard, Goffman made a distinction between those who are "discreditable" and those who are "discredited." While the former can attempt to hide their stigma, the latter, which would include wheelchair users, cannot. Cahill and Eggleston found that wheelchair users were treated as "non-persons" (Goffman, 1959, p. 152) in that they were frequently completely ignored in public encounters. Cahill and Eggleston also suggested that wheelchair users were treated as "open persons" (Goffman, 1966), who could be addressed without invitation in an over familiar manner. Further support for the idea that wheelchair use is stigmatizing is found in our research, which revealed a hierarchy of mobility for some residents who avoided the use of forms of assistive mobility technology that they saw as more disabling (Mortenson et al, 2005). For example, residents preferred scooters to manual wheelchairs to power wheelchairs.

- **Residents experience a variety of participation limitations.**

Observational studies have consistently found most residents spend large portions of their day involved in little or no activity (Gottesman & Bourestom, 1974; Ice, 2003, Voelkl, Winkelhake, Jeffries, & Yoshioka, 2003). Low levels of activity participation have also been identified in residents with dementia (Perrin, 1997). Most research that has explored predictors of participation among residents has focused on facility run recreational activities. Some

predictors of participation in facility recreational activities include cognitive ability (Voelkl, Fries, & Galecki, 1995), depression (Voelkl et al., 1995), and functional status (Kolanowski, Buettner, Litaker, & Yu, 2006). Studies looking at participation more generally in residents have found sensory impairments (Resnick, Fries, & Verbrugge, 1997) and functional status (Schroll, Jonsson, Mor, Berg, & Sherwood, 1997) are associated with social engagement. Research with wheelchair users has found that health (Hoenig et al., 2002), wheelchair fit (Hoenig et al., 2002), and accessibility (Hoenig et al.; McClain, Medrano, Marcum, & Schukar, 2000; Meyers, Anderson, Miller, Shipp, & Hoenig, 2002) are associated with participation. Only one study has looked at the relationship between individually prescribed wheelchairs and health-related outcomes. Using the SF-36 as an outcome measure, Trefler et al. (2004) found that health-related physical activity and social function improved with the provision of individualized wheelchair seating systems.

- **Quality of life is a concern in residential care.**

Many studies have raised concerns about the subjective well-being of facility residents. A study that used an objective, observational measure of well-being found that 82% of residents with dementia demonstrated poor to very poor well-being (Chung, 2004). Several studies have described the dehumanizing nature of many residential care facilities (Bland, 2007; Diamond, 1992; Fiveash, 1998; Gubrium, 1975; Kayser-Jones et al., 2003). An observational study of two residential care facilities found that interactions among residents and between residents and staff were negative 30% and 22% of the time in each facility respectively (Clark & Bowling, 1989, 1990).

- **Results comparing life satisfaction in residents and other populations are mixed**

Studies that have compared subjective well-being in residents and other populations have found inconsistent results. Some studies report that life satisfaction is the same among residents as it is among individuals living in the community (Crain, 2001; Loomis & Thomas, 1991; Madigan, Mise, & Maynard, 1996). Other studies indicate that life satisfaction is lower among residents (Crist, 1999; Gueldner et al., 2001; Patrick et al., 2000). Unfortunately, most of this research (with the exception of Patrick et al.) did not control for extraneous, confounding variables.

- **Some predictors of quality of life among residents have been identified.**

Several studies have identified predictors of quality of life among residents, but two caveats need to be acknowledged with this research. First, most research has focused exclusively

on residents with or without dementia, and so the findings may not generalize to the population as a whole. As well, for residents with dementia, research that has compared the use of subjective non-proxy measures and observational measures has found different predictors of quality of life depending on the measure used (Edelman, Fulton, Kuhn, & Chang, 2005). For self-responding residents, variables that predict quality of life include depression (Patrick et al., 2000), health (Bowsher & Gerlach, 1990; Ghusn, Hyde, Stevens, Hyde, & Teasdale, 1996; Patrick et al.) and functional ability (Patrick et al.). For residents with dementia, observational measures have identified dementia severity (Chung, 2004; Edelman et al.), functional ability (Ballard et al., 2001; Chung; Edelman et al.), and taking psychotropic medications (Ballard et al.) as independent predictors of quality of life. Using a subjective, non-proxy measure, however, Edelman and colleagues were unable to identify any predictors of quality of life in this population. No research has explored the relationship between wheelchair-related variables and quality of life in this population.

- **Improving the quality of life of nursing home residents is vital**

There is a wide spread assumption that the quality of life of residents is unalterably poor, which actually discourages efforts to improve it (Kane, 2003). Although it is important not to dismiss the suffering that many residents of residential care facilities experience (Forbes-Thompson & Gessert, 2006), if a society is to be judged on the way it treats its most vulnerable members (Humphrey, 1977), it is equally important to consider ways to improve their lives in order to avoid perpetuating the existence of institutions that are seen as places worse than death (Mattimore et al., 1997).

Research Question Development

This research is part of a program of wheelchair-related research that has included participants living in residential care (Bourbonniere, et al., 2007; Forward & Miller, 2000; Miller et al., 2004; Mortenson & Miller, 2008; Mortenson, et al., 2005; Mortenson, et al., 2006; Mortenson, Miller, & Miller-Polgar, 2007). We developed and refined our research questions based on a review of the literature and on the first author's clinical irritation with providing wheelchairs to residents that I felt did not meet their needs and were sometimes used as a means of preventing mobility. Given the limited research exploring the relationship among wheelchair use, mobility participation and quality of life outcomes and our desire to identify potential interventions to improve these outcomes, we envisioned a two-phase, research project. Recognizing the difficulty in understanding individuals independent of their environmental

contexts (Bourdieu, 1984; 1993; Iwama, 2006), in the preliminary phase of the research we wanted to develop a holistic understanding of what of what life was like for residents who used wheelchairs in these facilities. In light of the exploratory nature of our research, we also wanted to use the initial phase of the research as a way to identify measures for inclusion in the second phase of the research. In an earlier study, in two facilities with good access to wheelchair resources (Bourbonniere et al., 2007), we were able to account for a modest amount of variance in mobility scores (20%) using a small number of variables; and we found that need for seating intervention was the only significant predictor of mobility. In the second phase of the research, we wanted to extend this study in two ways. First, we wanted to include additional variables so that we could better model factors that influenced mobility among residents. Second, we wanted to include additional dependent variables so that we could explore the relationship among wheelchair related variables, mobility, participation and quality of life. We developed research questions that were inclusive of all facility residents who used wheelchairs to avoid replicating research that only studied sub-populations within such settings (i.e., residents with dementia or residents with no cognitive impairments) and thus did not provide a complete picture of the whole population.

Philosophical Foundation

This research stems from a transformative paradigm. From this perspective, social science inquiry should not only describe a phenomenon but also uncover how positive change can be facilitated (Habermas, 1970). In contrast to a post-positivist's ontological view that there is only one reality that can be known within a certain level of probability, and more in keeping with an interpretive-constructionist's perspective that there are multiplicity of viewpoints regarding the social world, a transformative perspective acknowledges "there are a diversity of viewpoints with regard to many social realities, but those view-points need to be placed within political, cultural, historical and economic value systems to understand the basis for the differences" (Mertens, 2003, p. 140). Research from this perspective is expected to not only explore the intersections of stratifications such as gender, class, age, and race, but it is also intended to identify the processes through which oppression is maintained (Collins, 2000). In contrast to a positivistic "view from nowhere" (Nagel, 1986) approach to objectivity, from a feminist/transformative perspective, Harding (1993, p. 54) notes, "knowledge claims are always socially situated." Transformative researchers, therefore, need to carefully consider "how their own acts of studying and representing people and situations are acts of domination even as [they]

reveal the same in what they study” (Noblit, Flores, & Murillo, 2004, p. 3). This requires us, as researchers, to contemplate our own positionality, especially in terms of the privileged positions that we occupy relative to our study participants (Stone & Priestly, 1996). In order to do so, Madison (2005, p. 9) indicates that we need to:

Attend to how our subjectivity *in relation to the Other* informs and is informed by our engagement and representation of the Other. We are not simply subjects, but we are subjects in dialogue with the Other. [Italics and capitalization in original]

In light of our philosophy, we tried to consider carefully how we as researchers had been involved in the research process, how we portrayed and labelled those who participated in our research, and how we brought our findings back to residents and staff at participating facilities as a means to encourage organizational change. Based on our underlying philosophical foundation, we felt that a mixed methods study would be helpful, as the qualitative data would enable the voices of residents to be heard and the quantitative data would be useful to help reinforce some of the qualitative findings and to lobby for institutional changes.

Use of Mixed-methods

The use of mixed-methods was a novel and appropriate approach for this study that has been suggested as a methodology for research conducted within a transformatory paradigm (Mertens, 2003). Mixed methods are useful as they allow theory generation and verification to take place within a single study and enable researchers to understand complex, multi-dimensional phenomena, like wheelchair use and mobility, from multiple perspectives (Tashakkori & Teddlie, 2003). In the qualitative phase 1 (described in Chapters 2 and 3), an ethnographic study was conducted in two different residential care facilities using a combination of extensive fieldwork; participant observation; in-depth; individual interviews; and review of wheelchair-related institutional policies and documents. In the quantitative phase 2, (described in chapters 4 and 5), a cross-sectional study was carried out to identify factors that predicted mobility, participation, and quality of life of residents in these settings. Given the exploratory nature of this research, the use of mixed-methods provided rich, meaningful data on this topic from both qualitative and quantitative perspectives. Both phases of the study were integrated, as the first phase informed the selection of measures used in the second phase and offered a means to contextualize and explain the quantitative findings (Creswell, Clark, Gutmann & Hanson, 2003; Teddlie & Tashakkori, 2003). The findings from the second phase of the study afford a complementary rather than corroboratory perspective on the topic (Moran-Ellis et al., 2006).

Overview

The findings from this research are presented in four empirical chapters. We provide a brief synopsis of the rationale, purpose, research questions, and contribution of each chapter below.

Chapter 2 – Grey Spaces: The Wheeled Fields of Residential Care

Rationale

In light of the prevalence of wheelchair use in residential care and the lack of current knowledge about how residents, families, and staff in these setting use wheelchairs and how residents experience this use, we conducted a critical ethnography. A critical ethnography differs from a traditional ethnography in that it explicitly acknowledges a moral imperative on the part of the researchers to address processes of injustice and oppression within a particular setting (Madison, 2005). Furthermore, critical ethnography explores taken-for-granted assumptions as a way of disrupting the *status quo* (Thomas, 1993).

Purpose

1. To examine how wheelchairs are used by residents, families, and staff in residential care settings.
2. To explore the perceptions and experiences of facility life among residents who use wheelchairs as their primary means of mobility.

Research Questions

1. How do residents, families, and staff in these settings use wheelchairs?
2. What are the experiences and perceptions of facility life among residents who use wheelchairs as their primary means of mobility?

Contribution

This research provides a venue for the voices of facility residents, their family members, and staff to be heard and aims to facilitate positive changes in their lives. The study identifies a variety of societal and institutional issues that residents need to contend with on a regular basis and suggests several policy and practice changes that could be considered. The findings of the study also help to contextualize the findings of our quantitative research by providing vivid description of institutional factors that might influence study outcomes.

Chapter 3 – Factors Related to Mobility, Participation, and Quality of Life among Individuals in Residential Care Who Use Wheelchairs as Their Primary Means of Mobility. An Exploratory Qualitative Study

Rationale

Given the limited research in this area, it is difficult to determine which are the most important constructs that are related to the mobility, participation, and quality of life of residents who use wheelchairs as their primary means of mobility. Although some research has explored the predictors of residents' participation and life satisfaction, wheelchair-related information is seldom recorded and may represent a confounding variable in these studies.

Purpose

- 1 To identify non-demographic factors that either enable or curtail the 1) mobility, 2) participation, and 3) life satisfaction of these residents and that would represent variables of interest for the second phase of the study.

Research Question

- 2 What non-demographic factors enable or curtail the 1) mobility, 2) participation, and 3) life satisfaction of residents who use wheelchairs as their primary means of mobility?

Contribution

This study helps residents, family members, staff, and administrators to understand how residents, families, and staff use wheelchairs in these settings and reveals the barriers and facilitators to mobility, participation, and life satisfaction that residents encounter. Data from this study indicated that physical ability, institutional factors, wheelchair skills, and wheelchair appropriateness were the most frequently identified factors related to mobility. Physical ability, finances, institutional factors, and assistance of friends and family were the most frequently identified factors associated with participation. Institutional factors, interactions with other residents, and assistance of friends and family were most frequently associated with quality of life in interviews and observations. By identifying variables of potential interest, this research lays the groundwork for the second, quantitative phase of the research.

Chapter 4 – Predictors of Mobility in Individuals in Residential Care

Rationale

Given the complexity of factors that influence wheelchair mobility in these settings, the poor equipment residents often receive, and the need to improve mobility among these individuals living in these settings, we conducted a cross sectional study with the following objective:

Purpose

1. To identify the independent predictors of mobility of residents who use wheelchairs as their primary means of mobility.

Research Questions and Hypotheses

1. What personal, wheelchair-related, and environmental factors predict mobility residents who use wheelchairs as their primary means of transportation?

Hypothesis: personal, wheelchair-related, and environmental variables will independently contribute to residents' mobility scores.

Contribution

By identifying the predictors of residents' mobility, this study will inform future intervention studies and other research in this area.

Chapter 5 – Predictors of Participation and Life Satisfaction among Long-Term Care Residents Who Use Wheelchairs as Their Primary Means of Mobility

Rationale

In light of methodological limitations of previous research that omitted wheelchair-related variables in the studies of predictors of participation and quality of life among residents and of the need to improve participation and quality of life in this population, we conducted a study with the following objectives.

Purpose

1. To explore the relationship among wheelchair-related factors and participation for residents who use wheelchairs as their primary means of mobility.
2. To examine the relationship among wheelchair-related factors and quality of life for these residents.

Research Questions and Hypothesis

1. What is the relationship between wheelchair-related factors and participation among residents living in long-term care facilities who use wheelchairs as their primary means of mobility?
2. What is the relationship between wheelchair-related factors and life satisfaction for these residents?

Hypothesis: wheelchair-related factors will be better predictors of participation rather than quality of life outcomes.

Contributions

For residents who use wheelchairs as their primary means of getting around, the study identifies the predictors of their participation and life satisfaction, some of which are amenable to

intervention. This research lays the groundwork for future research in this area, including experimental studies to improve these outcomes among residents.

References

- Assistive Technology Act of 1998, as Amended. Pub L. no. 108-364. Statute U.S.C. 3, 118 Stat. 1707 (2004).
- Baker, P. S., Bodner, E. V., & Allman, R. M. (2003). Measuring life-space mobility in community-dwelling older adults. *Journal of the American Geriatrics Society*, 51, 1610-1614.
- Ballard, C., O'Brien, J., James, I., Mynt, P., Lana, M., & Potkins, D. et al. (2001). Quality of life for people with dementia living in residential and nursing home care: The impact of performance on activities of daily living, behavioural and psychological symptoms, language skills, and psychotropic drugs. *International Psychogeriatrics*, 13, 93-106.
- Barker, D.J., Reid, D. & Cott, C. (2004). Acceptance and meanings of wheelchair use in senior stroke survivors. *American Journal of Occupational Therapy*, 58, 221-230.
- Bates, P.S., Spencer, J.C., Young, M.E. & Rintala, D.H. (1993). Assistive technology and the newly disabled adult: Adaptation to wheelchair use. *American Journal of Occupational Therapy*, 47, 014-1021.
- Baum, P.A., & Okun, M.A. (1983). Stability of life satisfaction in late life. *The Gerontologist*, 23, 261-265.
- Bendixen, R. M., Mann, W. C., & Tomita, M. (2005). The relationship of home range to functional status and cognitive status of frail elders. *Physical and Occupational Therapy in Geriatrics*, 23, 43.
- Bland, M. (2007). Betwixt and between: A critical ethnography of comfort in New Zealand residential aged care. *Journal of Clinical Nursing*, 16, 937-944.
- Bourbonniere M.C., Fawcett L.M., Miller, W.C., Garden J., & Mortenson W.B. (2007). Prevalence and predictors of need for seating intervention and mobility for persons in long-term care. *Canadian Journal on Aging*, 26, 195-204.
- Bourdieu, P. (1993). *Outline of a theory of practice* (R. Nice Trans.). New York: Cambridge University Press.
- Bourdieu, P. (1984). *Distinction: A social critique of the judgement of taste*. Cambridge, MA: Harvard University Press.
- Bowsher, J. E., & Gerlach, M. J. (1990). Personal control and other determinants of psychological well-being in nursing home elders. *Scholarly Inquiry for Nursing Practice*, 4, 91-102-108.

Brandt, A., Iwarsson, S., & Ståhle, A. (2004). Older people's use of powered wheelchairs for activity and participation. *Journal of Rehabilitation Medicine*, 36, 70-77.

Brechtelsbauer, D. & Louie, A. (1999). Wheelchair use among long-term care residents. *Annals of Long Term Care*, 7, 213-20.

Brienza, D.M., Karg, P.E., Geyer, M.J., Kelsey, S. & Trefler, E. (2001). The relationship between pressure ulcer incidence and buttock-seat cushion interface pressure in at-risk elderly wheelchair users. *Archives of Physical Medicine and Rehabilitation*, 82, 529-533.

Cahill, S.E. & Eggleston, R. (1995). Reconsidering the stigma of physical disability: Wheelchair use and public kindness. *Sociological Quarterly*, 36, 681-698.

Chung, J. C. C. (2004). Activity participation and well-being in people with dementia in long-term care settings. *Occupational Therapy Journal of Research*, 24(1), 22-31.

Clark, P., & Bowling, A. (1989). Observational study of quality of life in NHS nursing homes and a long-stay ward for the elderly. *Ageing and Society*, 9, 123-148.

Clark, P., & Bowling, A. (1990). Quality of everyday life in long stay institutions for the elderly. An observational study of long stay hospital and nursing home care. *Social Science & Medicine*, 30(11), 1201-1210.

Clarke, C., Chan, P., Santaguida, P.L., & Colantonio, A. (2009). The use of mobility devices among institutionalized older adults. *Journal of Aging Health Vol. 21*, 611-626.

Collins, P.H. (2000), Gender, black feminism, and black political economy. *The Annals of the American Academy of Political and Social Science*, 568, 41-53.

Crain, M. (2001). Control beliefs of the frail elderly. Assessing differences between homebound and nursing home residents. *Care Management Journals*, 3, 42-46.

Crane, B.A., Holm, M.B., Hobson, D., Cooper, R.A., Reed, M.P., & Stadelmeier, S. (2004). Development of a consumer-driven Wheelchair Seating Discomfort Assessment Tool (WcS-DAT). *International Journal of Rehabilitation Research*, 27, 85-90.

Creswell, J.W., Plano Clark, V.L., Gutmann, M.L. & Hanson, W.E. (2003) Advanced mixed-methods research designs. In A. Tashakkori, A. & C. Teddlie, C. (2003) (Eds.), *Handbook of mixed methods in social and behavioural research* (pp. 209-240). Thousand Oaks, CA: Sage.

Crist, P. A. (1999). Does quality of life vary with different types of housing among older persons? A pilot study. *Physical and Occupational Therapy in Geriatrics*, 16, 101-116.

Cutler, L.J., Kane, R.A., Degenholtz, H.B., Miller, M.J., & Grant, L. (2006). Assessing and comparing physical environments for nursing home residents: Using new tools for greater research specificity. *The Gerontologist*, 46, 42-51.

Desrosiers, J. (2005). Muriel Driver memorial lecture. Participation and occupation. *Canadian Journal of Occupational Therapy*, 72, 195-204.

Devitt, R., Chau, B., & Jutai, J. W. (2003). The effects of wheelchair use on the quality of life of persons with multiple sclerosis. *Occupational Therapy in Health Care*, 17, 63-79.

Diamond, T. (1992). *Making gray gold: Narratives of nursing home care*. Chicago, IL: University of Chicago Press.

Dimant, J. (2003). Avoiding physical restraints in long-term care facilities. *Journal of the American Medical Directors Association*, 4, 207-215.

Edelman, P., Fulton, B. R., Kuhn, D., & Chang, C. H. (2005). A comparison of three methods of measuring dementia-specific quality of life: Perspectives of residents, staff, and observers. *The Gerontologist*, 45 Spec No 1, 27-36.

Fiveash, B. (1998). The experience of nursing home life. *International Journal of Nursing Practice*, 4, 166-174.

Flaherty, J. H. (2004). Zero tolerance for physical restraints: Difficult but not impossible. *Journal of Gerontology A: Biological Sciences and Medical Sciences*, 59, M919 - M920.

Forbes-Thompson, S. & Gessert, G.E. (2006). Nursing homes and suffering: Part of the problem or part of the solution? *Journal of Applied Gerontology*, 25, 234-251.

Forward, J. A. & Miller, W.C. (2000). The prevalence of wheelchair and seating intervention needs in long-term care in London, Ontario. Unpublished research project, University of Western Ontario, London, Canada.

Fougeyrollas, P. Noreau, L., & Boschen, K. A. (2002). Interaction of environment with individual characteristics and social participation: Theoretical perspectives and applications in persons with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation*, 7, 1-16.

Fuchs, R.H. & Gromak, P.A. (2003). Wheelchair use by residents of nursing homes: Effectiveness in meeting positioning and mobility needs. *Assistive Technology*, 15, 151-163.

Ghusn, H. F., Hyde, D., Stevens, E. S., Hyde, M., & Teasdale, T. A. (1996). Enhancing life satisfaction in later life: What makes a difference for nursing home residents. *Journal of Gerontological Social Work*, 26, 27-47.

- Goffman, E. (1959). *The presentation of self in everyday life*. Doubleday Garden City, NY.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Prentice-Hall Englewood Cliffs, NJ.
- Goffman, E. (1966). *Behaviour in public places*. New York: Free Press.
- Gottesman, L. E., & Bourestom, N. C. (1974). Why nursing homes do what they do. *The Gerontologist*, 14, 501-506.
- Gubrium, J.F. (1975). *Living and dying at Murray Manor*. New York: St. Martin's Press.
- Gueldner, S. H., Loeb, S., Morris, D., Penrod, J., Bramlett, M., & Johnston, L. et al. (2001). A comparison of life satisfaction and mood in nursing home residents and community-dwelling elders. *Archives of Psychiatric Nursing*, 15, 232-240.
- Habermas, J. (1970). Knowledge and interest. In D. Emmett and A. MacIntyre (Eds.), *Sociological Theory and Philosophical Analysis*. London, England: MacMillan.
- Harding, S. (1993). Rethinking standpoint epistemology: What is strong objectivity? In L. Alcoff & E. Potter (Eds.), *Feminist epistemologies* (pp. 49-82). New York: Routledge.
- Health Care Financing Administration (1992). *Interpretive Guidelines. State Operations Manual*. Washington, D.C: Author.
- Hoening, H., Landerman, L. R., Shipp, K. M., & George, L. (2003). Activity restriction among wheelchair users. *Journal of the American Geriatrics Society*, 51, 1244-1251.
- Hoening, H., Pieper, C., Zolkewitz, M., Schenkman, M., & Branch, L. G. (2002). Wheelchair users are not necessarily wheelchair bound. *Journal of the American Geriatrics Society*, 50, 645-654.
- Humphrey, H.H., (1977). Remarks at the dedication of the Hubert H. Humphrey Building, November 1, 1977. *Congressional Record*, 123, 37287.
- Ice, G. H. (2002). Daily life in a nursing home: Has it changed in 25 years. *Journal of Aging Studies*, 16, 345-360.
- Iwama, M. *The Kawa model. Culturally relevant occupational therapy*. New York: Churchill Livingstone.
- Kayser-Jones, J., Schell, E., Lyons, W., Kris, A.E., Chan, J., & Beard, R.L. (2003). Factors that influence end-life care in nursing homes: The physical environment, inadequate staffing, and lack of supervision. *The Gerontologist*, 43, 76-84.

Kane, R.A. (2003). Definition, measurement, and correlates of quality of life in nursing homes: Toward a reasonable practice, research, and policy agenda. *Gerontologist*, 43 (2), 28-36.

Kolanowski, A., Buettner, L., Litaker, M., & Yu, F. (2006). Factors that relate to activity engagement in nursing home residents. *American Journal of Alzheimer's Disease and Other Dementias*, 21, 15-22.

Krasilovsky, G. (1993). Seating assessment and management in a nursing home population. *Physical & Occupational Therapy in Geriatrics*, 11, 25-38.

Loomis, R., & Thomas, C. (1991). Elderly women in nursing home and independent residence: Health, body attitudes, self-esteem and life satisfaction. *Canadian Journal on Aging*, 10, 224-231.

Madigan, M., Mise, D., & Maynard, M. (1996). Life satisfaction and level of activity of male elderly in institutional and community settings. *Activities, Adaptation and Aging*, 21, 21-36.

Madison, D.S. (2005). *Critical ethnography. Methods, ethics and performance*. Thousand Oaks, CA: Sage.

Mann, W. C., Llanes, C., Justiss, M. D., & Tomita, M. (2004). Frail older adults' self-report of their most important assistive device. *Occupational Therapy Journal of Research*, 24, 4-12.

Mattimore, T.J., Wenger, N.S., Desbiens, N.A., Teno, J.M., Hamel, M.B., Liu, H., Califf, R., Connors, A.F., Lynn, J. & Oye, R.K. (1997). Surrogate and physician understanding of patients' preferences for living permanently in a nursing home. *Journal of the American Geriatrics Society*, 45, 818-824.

McClain, L., Medrano, D., Marcum, M., & Schukar, J. (2000). A qualitative assessment of wheelchair users' experience with ADA compliance, physical barriers, and secondary health conditions. *Topics in Spinal Cord Injury Rehabilitation*, 6, 99-118.

Mertens, D. (2004). *Research and evaluation in education and psychology. Integrating diversity with quantitative, qualitative and mixed methods*. (2nd ed.). Thousand Oaks, CA: Sage.

Meyers, A.R., Anderson, J.J., Miller, D.R., Shipp, K., & Hoenig, H. (2002). Barriers, facilitators, and access for wheelchair users: Substantive and methodologic lessons from a pilot study of environmental effects. *Social Sciences and Medicine*, 55, 1435-1446.

Mitchell, J.M., & Kemp, B.J. (2000). Quality of life in assisted living homes: A multidimensional analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 55, 117-127.

Morgan-Ellis, J., Alexander, V. D., Cronin, A., Dickinson, M., Fielding, J., Slaney, J., & Thomas, H. (2006). Triangulation and integration: Processes, claims and implications. *Qualitative Research, 6*, 45–59.

Mortenson, W.B., & Miller, W.C. (2008). The wheelchair procurement process: perspectives of clients and prescribers. *Canadian Journal of Occupational Therapy, 75* (3), 177-185.

Mortenson, W.B., Miller, W.C., Boily, J., Steele, B., Odell, L. Crawford, E.M. et al. (2005). Perceptions of power mobility use and safety within residential facilities. *Canadian Journal of Occupational Therapy, 72*, 142-152.

Mortenson, W.B., Miller, W.C., Boily, J., Steele, B., & Crawford, E.M. & Desharnais, G. (2006). Overarching principles and salient findings for inclusion in guidelines for power mobility use within residential care facilities *Journal of Rehabilitation Research and Development, 43*, 199-208.

Mortenson W.B., Miller, W.C., & Miller-Polgar, J. (2007). Measuring wheelchair intervention outcomes: Development of the wheelchair outcome measure. *Disability and Rehabilitation. Assistive Technology, 2* (5), 275 - 285.

Nagel, T. *The view from nowhere*. New York: Oxford University Press.

Noblit, G.W., Flores, S.Y., & Murillo, E.G. (2004). Postcritical ethnography: An introduction. Cress, NJ: Hampton Press.

Patrick, D. L., Kinne, S., Engelberg, R. A., & Pearlman, R. A. (2000). Functional status and perceived quality of life in adults with and without chronic conditions. *Journal of Clinical Epidemiology, 53*, 779-785.

Peel, C., Baker, P. S., Roth, D. L., Brown, C. J., Bodner, E. V., & Allman, R. M. (2005). Assessing mobility in older adults: The UAB study of aging life-space assessment. *Physical Therapy, 85*, 1008-1019.

Perrin, T. (1997). Occupational need in severe dementia: A descriptive study. *Journal of Advanced Nursing, 25*(5), 934-941.

Reed, R.L., Yochum, K., Schloss, M. (1993). Platform motorized wheelchairs in congregate care centers: A survey of usage and safety. *Archives of Physical Medicine and Rehabilitation, 74*, 101-103.

Resnick, H. E., Fries, B. E., & Verbrugge, L. M. (1997). Windows to their world: The effect of sensory impairments on social engagement and activity time in nursing home residents. *The Journals of Gerontology Series B, Psychological Sciences and Social Sciences*, 52, S135-44.

Routhier, F., Vincent, C., Desrosiers, J. & Nadeau, S. (2003). Mobility of wheelchair users: a proposed performance assessment framework. *Disability and rehabilitation*, 25, 19 -34.

Sapey, B. H., Stewart, J. H., & Donaldson, G. H. (2005). Increases in wheelchair use and perceptions of disablement. *Disability and Society*, 20, 489-505.

Schroll, M., Jonsson, P. V., Mor, V., Berg, K., & Sherwood, S. (1997). An international study of social engagement among nursing home residents. *Age and Ageing*, 26 Suppl 2, 55-59.

Shaw, G. & Taylor, S.J. (1991). A survey of wheelchair seating problems of the institutionalized elderly. *Assistive Technology*, 3, 5-10.

Shields M. (2004). Use of wheelchairs and other mobility support devices. *Health Reports*, 15, 37-41.

Simmons, S. F., Schnelle, J. F., MacRae, P. G., & Ouslander, J. G. (1995). Wheelchairs as mobility restraints: Predictors of wheelchair activity in nonambulatory nursing home residents. *Journal of the American Geriatrics Society*, 43, 384-388.

Smithers, J.A. (1990). A wheelchair society: The nursing home scene. *Journal of Aging Studies*, 4, 261-275.

Statistics Canada. (2005) *Population Projections for Canada, Provinces and Territories, 2005 to 2031*. Catalogue no 91-520-XIE. Ottawa, Ontario: Statistics Canada, 2005. Available on line at <http://www.statcan.ca/english/freepub/91-520-XIE/0010591-520-XIE.pdf>

Stone, E. and Priestley, M. (1996). Parasites, pawns and partners: disability research and the role of non-disabled researchers. *British Journal of Sociology*, 47, 699-716

Tashakkori, A. & C. Teddlie, C. (2003) (Eds.), *Handbook of mixed methods in social and behavioural research*. Thousand Oaks, CA: Sage.

Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, CA: Sage.

Tinetti, M.E. & Ginter, S.F. (1990). The nursing home life-space diameter. A measure of extent and frequency of mobility among nursing home residents. *Journal of the American Geriatrics Society*, 38, 1311-1315.

Trefler, E., Fitzgerald, S.G., Hobson, D.A., Bursick, T. & Joseph, R. (2004). Outcomes of wheelchair systems intervention with residents of long-term care facilities. *Assistive Technology*, 16, 18-27.

Voelkl, J. E., Fries, B. E., & Galecki, A. T. (1995). Predictors of nursing home residents' participation in activity programs. *The Gerontologist*, 35, 44-51.

Voelkl, J. E., Winkelhake, K., Jeffries, J. & Yoshioka, N. (2003). Examination of a nursing home environment: Are residents engaged in recreation activities? *Therapeutic Recreation Journal*, 37, 300-314.

World Health Organization. (2002a). *ICF. International classification of functioning disability and health*. Geneva, Switzerland: World Health Organization.

World Health Organization. (2002b). *Towards a common language of function, disability and health: ICF*. Geneva, Switzerland: World Health Organization. Retrieved Mar 17, 2006, from <http://www3.who.int/icf/beginners/bg.pdf>

Chapter 2: Grey Spaces: The Wheeled Fields of Residential Care ¹

Residential care facilities house older individuals with a variety of diagnoses and functional limitations. In North America, admissions increase with age, the proportion more than doubling for every decade over 65 (Sahyoun, Pratt, Lentzner, Dey, & Robinson, 2001; Statistics Canada, 2007). Most residents are white women (Sahyoun et al.), and most staff members who provide resident care are women of color (Diamond, 1992; Reed-Danahay, 2001). Most residents have multiple diagnoses, almost half have dementia (Harrington, Carrillo & Blank, 2008), and the majority require the use wheelchairs as a means of mobility (Harrington, Carrillo & Blank, 2008; Shields, 2004).

Although the benefits of properly prescribed and fitted wheelchairs in residential care have been documented (Trefler, Fitzgerald, Hobson, Bursick, & Joseph, 2004), the chairs that residents receive are frequently inadequate. Wheelchair-related problems including discomfort, poor posture, and hindered mobility have been identified in 46% to 80% of wheelchair users (Simmons, Schnelle, MacRae, & Ouslander, 1995; Shaw & Taylor, 1991). Wheelchair-related pressure ulcers (Brienza, Karg, Geyer, Kelsey & Trefler, 2001) and attitudinal barriers in the community are problems for residents in care facilities (Mortenson et al, 2005).

A variety of ethnographic studies have been conducted in residential care facilities. Many have described the dehumanizing and discomfiting experiences of residents (Bland, 2007; Diamond, 1992; Fiveash, 1998; Gubrium, 1975; Kayser-Jones et al., 2003). Some researchers have also investigated the difficulties encountered by nursing home assistants and other staff as they try to deliver care in under-resourced settings (Diamond, 1993; Kayser-Jones et al., 2003; Reed-Danahay, 2001). Despite the prevalence of wheelchairs in residential care, few recent ethnographic studies have explored the role that wheelchairs play in this setting. Gubrium (1975) explained how wheelchairs were used by staff to “warehouse” confused residents by restraining them in their wheelchairs. Smithers’ (1990) found residents used wheelchairs to extend their mobility, which improved their sense of control within their environmental and well-being. From a geographical gerontological perspective, residential care facilities have been described as sites of spatial and social restraint rather than therapeutic landscapes that promote well-being (Andrews, Cutchin, McCracken, Philips, & Wiles, 2007; Andrews & Peter, 2006).

¹ A version of this chapter will be submitted for publication. Mortenson, W.B., Oliffe, J.L., Miller, W.C., & Backman, C.L. Title: Grey spaces: The wheeled fields of residential care.

Given the prevalence of wheelchair use in residential care facilities and potential for their misuse, we carried out an ethnographic study to develop contemporary understandings of the lives of residents who use wheelchairs in these settings. Specifically we sought to understand:

1. What are the experiences and perceptions of facility life among residents who use wheelchairs as their primary means of mobility?
2. How do residents, families, and staff in these settings use wheelchairs?

Theoretical Framework

This study used a critical realist lens to help comprehend how participants' understandings are shaped by political, cultural, historical, and economic value systems (Denzin & Lincoln, 2005). It was informed by Pierre Bourdieu's interrelated constructs of habitus, capital and field (Bourdieu, 1984). Habitus refers to acquired dispositions that provide individuals with the tools they need to compete in the fields that they occupy (Bourdieu, 1993). Residents' habitus includes their preferences in terms of food and daily routines and the manner in which they present themselves and make requests. Fields are relatively autonomous social microcosms; each field has its own rules that specify which forms of capital are most lucrative (Bourdieu, 1984). A residential care facility can be conceptualized as a field, but within each facility are smaller subfields, which include nursing units, wings, hallways, and rooms. Capital has both material and immaterial forms that can be transformed into power at varying rates of conversion (Bourdieu, 1984). Symbolic, social, economic, cognitive and physical are forms of capital that enable residents to get the things they want and need, which could include finances, social status or ability to mobilize independently. The constructs of habitus, capital and field combine to produce social practices, which Bourdieu (1984, p. 101) expresses with the formula: "[habitus (capital)] + field = practice." As unexpected events frequently precipitate admissions, residents' pre-admission habitus and capital may leave them unprepared for the life inside these new fields. This creates the potential for habitus mismatch, a situation in which an individual's resources are incongruent with the demands of his or her environments (Bourdieu, 2001). For this research, we did not employ Bourdieu's concepts prescriptively but instead used them as a framework to critically think about and inductively to derive meanings from the data. For a more in-depth description of Bourdieu's methodological constructs, please see Appendix 1.

Methods

Study Design

Critical ethnography was selected as the research methodology, given the researchers' desire to understand the culture of wheelchair use and commitment to fostering positive change within these settings (Thomas, 1993). The study, approved by the local university ethics board (as noted in Appendix 2), employed a multi-method qualitative design that included fieldwork, participant observation, in-depth interviews and review of institution policy documents.

Study Settings

Facility 1 was a 200-bed multi-floor, government funded residential care facility with good access to wheelchair equipment. Facility 2 was a similar facility with less access to wheelchair equipment. Both facilities had adopted the Eden alternative, a philosophy of care that promotes resident-centred care and resident input into facility decision-making (Thomas, 1994). Approximately 40% of residents were immigrants from China. More than 90% of residents used a wheelchair as their primary means of mobility, and most were in their final years of life. These facilities had three wards with 60-75 resident beds. Each ward had a nursing station where medical records were stored and staff charted and a large common dining/recreational area. Most residents shared their room with three other residents. Each resident had approximately nine square feet of space, furnished with a hospital bed, small dresser, clothes cupboard, and wheeled bedside table.

Eligibility and Recruitment

To be included in the study, residents needed to use a wheelchair to get from their room to the common room on each floor. We purposively sampled residents for maximum theoretical variation in terms of 1) cognitive ability, 2) cultural background, 3) independence or dependence propelling wheelchairs, 4) indoor only or in and outdoor wheelchair use, and 5) type of wheelchair (power, manual or tilt-in-space (a wheelchair with a seat that can be tilted backwards on the wheeled base)). We purposively sampled staff from five different professional groups at each facility. Potential participants (staff and residents or their surrogate decision makers) were invited to participate in the study by a staff member at each facility who was not associated with the research. Based on their knowledge of the residents, these staff members determined whether residents were able to participate meaningfully in interviews and to understand the risks involved in participating in the research well enough to provide their own informed consent. Surrogate decision makers provided consent for residents who could not provide their own consent, and

their assent was obtained to participate in the study. We obtained verbal consent/assent from other residents, family members, and staff to be included in observations with residents.

Data Collection

The primary author and two trained research assistants collected the data. We conducted two or three participant observations of two to four hours with resident participants to examine how wheelchairs were used inside and outside the facility by residents, staff, and families. These observations focused on the study participants but also included general notes about the types and features of wheelchairs used at each facility. Observations recorded how residents, family members, and staff used wheelchairs, where residents went, what they did, and how they interacted with others. We conducted a series of two or three individual in-depth interviews with residents and/or family member designates for residents who were not able to provide their own consent. We conducted singular individual interviews with staff and some additional family members and residents. During interviews, we asked residents or their designates to describe a typical day, including the activities they did, locations they went, and assistance they were provided; and we asked staff to describe the help they provided to residents and the wheelchair-related policies and procedures they followed. Each individual interview lasted approximately one hour and were digitally recorded, transcribed verbatim, and checked for accuracy. We also recorded interview notes detailing key interview content, participant's nonverbal behaviours, and researchers' reflections on the interview process. We studied institutional policy documents to examine the written procedures guiding facility wheelchair-related practices. Please see Appendix 3 for examples of participant observations and interview guide questions.

Participants

Sixteen residents participated in ongoing participant observations-- an equal number from each facility. Thirteen of these residents, four family members (one husband and three adult children), and one paid companion participated in the ongoing individual interviews, including two residents who were not competent to provide consent but did contribute during interviews with their family members. One resident and two family members of self-responding residents also participated in individual interviews. The 17 resident participants, including those observed or interviewed, ranged in age from 55 to 96 years (mean=80 years (SD= 11)). Twelve used manual wheelchairs and five used power wheelchairs, and they had six months to 52 years of experience using a wheelchair. Three were unable to propel their wheelchairs independently. Seven spoke English as a second language, including three Chinese speakers. They had lived in

the facility for three months to four years (mean =1.7 years (SD=1.1). Residents (number in brackets) had a variety of comorbid diagnoses including dementia (3), stroke (2), spinal cord injury (3), arthritis (4), diabetes (8), macular degeneration (4), osteoporosis (1), and trauma (1). We also interviewed five staff members from each facility (two resident care aides, two physical therapists, two occupational therapists, two nurses, one activity worker, and one rehabilitation assistant). They had an average of 17 years experience (range = 2 to 30 years, SD=10.7) in their various professions and eight years experience at the study facilities (range = 6 months to 20 years, SD=8.1).

Data Analysis

Analysis was ongoing during the data collection process. By repeatedly reading the interview transcripts and observations and interview notes, we identified initial concepts and developed preliminary interpretations. We further explored these ideas in subsequent interviews and participant observations to refine the analysis and to test emerging theories about wheelchair use and participant experiences (Thorne, Reimer Kirkham & MacDonald-Emes, 1997). Using this analytic logic, we developed broad categories to organise and code raw data inductively and to identify themes within and across participants and facilities (Morse & Field, 1995). We analyzed the content of institutional documents to develop contextual understandings about the rules and regulations governing practice within each facility.

Reflexivity, triangulation, and member checking helped ensure the trustworthiness of the analyses and findings. Fieldwork, interview notes, and memos served as reflexive tools to detail the analytic process as well as acknowledge the privileged position and perceptions that able-bodied researchers can impose (McIntosh, 1988). Multiple data sources and methods of collection were forms of triangulation that offered a variety of perspectives on wheelchair use in these settings. In addition, observations, interviews, and content analyses of existing policy documents facilitated the development of thick descriptions. This approach was especially useful because there can be a significant difference between policy and practice as well as between what people say and do. Member checking allowed participants to review the preliminary study findings, provided feedback about the conclusions drawn from the data, and served as an additional source of data during the final analysis. Please see Appendix 4 for a detailed description of the member checking process.

Findings

We identified three themes through our analysis. *Ready to roll?* described how wheelchairs were used by residents and staff members in different ways. *Squeaky wheels* illustrated the help that residents required, issues they experienced with the timing and quality of this assistance, and some strategies they employed to get their needs met. *In, out and about* revealed diversity in the places residents went, spaces they shared, and the social activities they engaged in outside and inside in their facilities. We used pseudonyms to conceal the identity of participants and their facilities.

Ready to Roll?

Wheelchairs were a critical form of capital for residents and staff that were closely related to mobility and comfort. Appropriately fitted wheelchairs could facilitate mobility, as Rita, a 90-year-old resident who used a manual wheelchair, described:

When I first came I brought my own wheelchair but [it was] too high and my feet couldn't reach [the floor]. When I got this wheelchair [designed for foot propelling], I felt like a new person. Then I could go on my own again [and do what] I wanted.

Having a wheelchair they could self-propel was vital for residents, because staff were not always available to help move them. Henry, a power mobility user, noted that if he could not move himself he would be stuck wherever staff parked him, because “they don't want to push me -- they don't have the time to do that.” All interviewees had wheelchairs that could potentially be self-propelled; however, our observations revealed some other residents had “transport chairs” with no potential for self-propulsion, as the resident's feet were unable to touch the ground and/or the wheelchairs lacked large rear wheels necessary for upper extremity propulsion. Although we were unable to determine whether those residents were capable of self-propulsion, this practice raises the possibility that some residents were restrained in chairs that they could not move, a practice previously documented by Gubrium (1975) and Smithers (1990).

Most participants were in their chairs more than 10 hours per day, so having a comfortable chair was also important. Lana, an occupational therapist, pointed out, “If you need a nap in the afternoon, we just don't have enough manpower to get people up down up down.” Some participants had difficulty with self-repositioning and reported instances of skin breakdown from prolonged sitting. Bill's son explained how a special air cushion and tilt-in-space chair was recommended for his father, a 90-year-old resident with a history of pressure ulcers, “because [he] spends so much time in the chair.” Zack, a 75-year resident with a spinal

cord injury, relied on the power tilt function of his power wheelchair for repositioning, “because if [“my butt’s not back”...] then I slouch [...] and it’s not comfortable. [...If] I slip, [...] a bit during the day [then] I can tip back [...] and then I just sort of adjust myself.” In this case, his power tilt chair gave him the opportunity to shift his weight in the chair but added \$3000 to the cost of the chair. Participants in power tilt chairs frequently self-adjusted their positioning by this tilt function. Residents in manual tilt chairs were reliant on staff and family or paid companions to tilt them. For example, Bill indicated staff only tilted his wheelchair once per day, whereas for Rose, an 85-year-old woman with an extensive cerebral vascular accident (CVA), the paid companion regularly changed the tilt angle, “to give her comfort.” In these examples, wheelchair and social capital could improve comfort and reduce the likelihood of developing pressure ulcers, which have been identified as a serious complication in these settings (Lynn et al., 2007).

Given lower quality wheelchair equipment at Facility 2, residents were encouraged to purchase their own chairs. As one occupational therapist explained, “We have a lot [of wheelchairs], but they’re not the best. A lot of families come in and they don’t have the funding.” Residents in Facility 2 with financial resources could purchase better wheelchairs and therefore attain additional physical capital that might facilitate mobility and foster participation. Residents without these resources needed to use facility chairs, which may not be optimal for them (Miller, Miller, Grant, Trenholm, & Goodman, 2004; Simmons et al., 1995; Shaw & Taylor, 1991).

Although wheelchairs facilitated mobility, there were some negative outcomes associated with their use; and we often observed minor accidents. A nurse noted, “We have a couple of people [with dementia who...] tend to run into people by accident, and it really gets the other people upset. [...] It’s really hard to try and redirect them. There’s not enough space for all these wheelchairs.” Accidents in power wheelchairs were especially problematic, because --in accordance with facility policies-- these could result in removal of power mobility as Ernie, an 80-year-old resident, pointed out: “[You] need to control yourself and not run into someone [...] otherwise] they’ll take [your power wheelchair] away.” These residents had only limited control over the wheeled capital they possessed. Similarly, Mortenson et al. (2005) found lack of adequate space contributed to wheelchair accidents in residential facilities, and such events sometimes precipitated a resident’s loss of power mobility.

Staff used wheelchairs to help manage and control residents. Residents’ wheelchairs were labelled with their names and room numbers, and this enabled staff to keep track of equipment

and residents. Residents at risk for absconding, a practice termed “eloping” in these settings, frequently had devices installed on their chairs that would lock doors or deactivate elevators to prevent them from leaving designated areas. Staff often applied brakes to resident’s wheelchairs at meal times; but Isabel, a care aide, reported many residents were able to release them. “At lunch time we put the brakes on otherwise they leave. It doesn’t mean if you put the brake on, they will stay. They undo [them...] When the lunch is here [...] most of them are gone somewhere.” Some observations supported this assertion, but contrasts research by Simmons et al. (1995) that found no residents could release their brakes independently. This difference likely relates to the advent of standard-issue, extended-handle brake levers that decrease the force required to release brakes.

Both the facilities in this study had practice guidelines and policies limiting the use of restraints and devices that were designed with the *intent* to restrict a resident’s mobility. Despite the advent of the guidelines, Wendy, an occupational therapist, noted, “I think there is still some confusion over what is considered a restraint and what isn’t.” Several staff talked about using wheelchair lap trays that were secured behind the wheelchair or tilt-in-space wheelchairs to prevent residents from getting out of their chairs but did not define this as a restraint, yet the practice contravened facility policy.

In these cases, defining a restraint based on its intent seemed to create potential for misuse. Instead, it may be more helpful to define restraints, as is frequently done, based on the outcomes they produce (i.e., preventing free movement of the body) (Castle & Mor, 1998), especially in light of the potentially lethal consequences associated with their use (Capezuti et al., 2008). In both settings, cognitive capital, in the form of competence, allowed some residents to transfer at risk, while others were restrained. Diminished cognitive capital may be one reason why residents with cognitive impairment are more likely to be restrained (Philips et al. 1996). Although higher rates of restraint use have been associated with lower staffing levels (Philips et al.), in a study that controlled for resident characteristics, Pekkarinen et al. (2006) found that increasing workload only increased the use of restraints when nurses also reported low levels of autonomy.

Squeaky Wheels

Although wheelchairs enabled mobility and provided other benefits, participants also needed assistance to perform a variety of tasks. Those who needed help transferring often had to wait for assistance, as there was only one resident care aide for every six or seven residents

during the day shift. Robert, an 85-year-old resident with a CVA, who was supposed to wait for staff to assist him, explained that after ringing the call bell to go to the washroom he waited, “15 minutes, 30 minutes and nobody came. I went to the toilet and I finished before they came [and asked]... ‘What do you want?’” The staffing levels at these facilities were similar to other facilities in the area, but below those recommended by some researchers (Maas, Specht, Buckwalter, Gittler & Bechen, 2008). In light of the amount of assistance available, the ability to transfer represented a critical form of bodily capital, like the ability to walk for community dwelling individuals with disabilities (Edwards & Imrie, 2003).

Many participants wanted to regain the ability to transfer independently. To accomplish this, Robert’s family paid for additional physiotherapy and practiced exercises with him several times per week, as a means to help him secure that ‘extra’ physical capital. One family member performed manual lifts with his wife, Josephine, a resident in her mid-eighties with dementia, in an effort to reduce the waiting. As James described, “I will get her out of the chair and lift [...] her on the bed.” Having family available to help provided valuable additional capital for residents, a common form of assistance in residential care (Gaugler, 2005).

When residents needed assistance to transfer, staff controlled when and how they could get into and out of their wheelchairs. A “no-lift” policy in both facilities meant that staff used mechanical lifts for residents who could not weight bear. One issue with the use of mechanical lifts involved whether staff left the transfer sling under the resident when he or she was sitting in the wheelchair. Zack offered some reasons for leaving slings under residents and described the conflict between health disciplines in this regard:

[On the other ward], I [...] had the regular sling in behind me. And the reason being, the care aide’s convenience and for ease on their bodies leave it in all the time. And that frankly, is an issue between [occupational therapists] and nursing. [...] It’s a question of care aide’s arms and shoulders against Zack’s butt.[...] And so what they say is get out of the chair – go back to bed for awhile. That’s the care aide’s solution. But now that I’ve moved here, [they] use the toileting sling. It’s easy to put in. I just lean forward and they put it in.

In contrast, care aides described the dangers of trying to put slings back under residents who were potentially violent as Tim depicted, “we have one resident who’s very, very aggressive and he swings his arms when you’re trying to get the sling under him so they basically say, ‘once you get him up, leave the sling in him [...] otherwise somebody is going to get belted.’ ” Resident

safety was also a concern, as they could be injured if slings were not put back in the correct position, as Isabel, a care aide, noted, “[If] We can't really push it all the way down and then when you lift the resident then the sling kind of rides up. It's scary.” Some interdisciplinary tension existed regarding sling use, as Wendy, an occupational therapist, noted, “Because you learn in school, [to avoid] layers between someone and their wheelchair cushion. [...] I've had to advocate for some residents [to get the slings removed].” These accounts reveal the complexity of care provision in these facility settings. For example, staff from different disciplines may compete in these ‘shared’ fields, leaving some residents caught between interdisciplinary struggles, perhaps searching for some capital leverage within that dominant milieu.

Some residents, depending on their capital and pre-admission habitus, were able to optimize meeting their own needs, especially those who were better able to interact with staff. James, a family member, pointed out: “You get what you give. If you learn [the] names [of the staff] and you [chat] with them a little bit. They [help you more readily].” Pearl, a 78-year-old resident with a stroke and limited social and economic capital, had difficulty getting assistance because she noted, “I have to ask and they're not here all of the time [...] and I don't want to impose.” Her sentiment reflects a form of symbolic violence in these fields that make low staffing levels seem like an inevitable and natural feature of residential care facilities (Bourdieu, 1993). By accepting these institutional limitations as part of the *status quo*, responsibility for problems is shifted from society to the individual and the impetus for change is diminished (Edwards & Imrie, 2003).

Due to resource limitations, residents, in essence, competed with one another for staff time. Most participants identified residents who received special treatment that decreased the help available to others. Pearl, in describing her roommate, quipped, “She's number one, she has to be first. She's very hoity toity. [...] She's always hanging around trying to get somebody to push her. Putting on the ‘oh it's so difficult’ act.” Pearl felt this act, stemming from her roommate's habitus, made the roommate's needs seem more important. Two participants indicated that men in the facility received preferential treatment over women. Pearl reported that the four men in the room nearby hers, “always want something. [...] There are two or three care aides in there at once a lot of the time.” The gender-related capital and habitus these men possessed may have contributed to the care they received—reproducing, in effect, the power relations which exist outside of these facilities (McIntosh, 1988). Staff also observed the squeaky wheel strategy for getting needs met:

The people who ask get and the ones who are sort of passively waiting for something [can get overlooked]. You don't try to consciously do it but you end up doing it just because the other ones [...] are always asking or are always [...] available and making your job easier for you.

These passive and less demanding residents seemed to experience a habitus mismatch, as their preadmission dispositions and current abilities were incongruent with the demands of life inside these facilities (Bourdieu, 2000).

Residents with cognitive impairment had the greatest challenges getting their needs met. In describing the care provided to his wife Josephine, James noted, “[Residents with dementia] get what care is necessary, but no more. And it’s gonna be on a timetable, not necessarily when they want it. [...because...] they’re not pushing their [call bells] if they are being ignored.” Differences in care provided to residents with less cognitive capital have also been noted in provision of palliative care (Kayser-Jones, 2002) and pain management given to residents with cognitive impairment (Reynolds, Hanson, DeVellis, Henderson, & Steihauser, 2008).

In general, most participants and families were satisfied with the care they received, as Karl, a 55-year-old manual wheelchair user, asserted, “They’re an excellent staff. I like them. They’re all good.” A few residents, however, voiced concerns. Ellen, an 85-year-old resident, indicated, “when I came here they wanted me to go to bed at 7 o'clock [...in the evening...] and they did a bullying act with me to coerce me into going to bed.” However, this resident, a self-described, “in your face type” refused, “I said, ‘I’m not going until [...] 10:30,’ and [...] ‘You can’t make me and I won’t.’” Rita complained that care aides would “talk another language over the patients,” which she found disconcerting. Such practices likely contribute to communication issues common in these settings (Mold, Fitzpatrick, Roberts, 2005).

Some tensions between residents and staff may have resulted from the different objectives each group had. Lana, an occupational therapist, indicated that her work focused on “the four Ss’: skin [integrity], swallowing, seating, and safety.” Whereas residents were trying to get their individual needs met, staff tried to meet the needs of many residents with the resources that were available. Cheryl, a nurse, explained,

The patients are a lot sicker and lot heavier than what they used to be [...but staffing levels have] pretty much stayed the same.” [...] “Depending on how busy you are, you may not be able to get certain people up everyday. [...] There’s not always enough time in the day to do it.

In this way, staff habitus appears heavily influenced by the workloads within these fields. Furthermore, broader socio-political forces impacted care giving, as one activity worker observed,

There's morale problems in the staff and it has a lot to do with the staffing model, the government cuts, the breaking of the contract, cutting our wages and I'm sure there's still a lot of resentment over that and it's wrong but it sometimes comes out at work.

Kayser-Jones et al. (2003) suggested that it is easy to vilify the staff in these settings, but this ignores how institutional factors such as staffing levels and work conditions shape the care they can provide. Since 2002, a series of British Columbia government bills broke previously negotiated union contracts, facilitated health sector privatization, forced striking workers to return to work, and attempted to prevent union reformation in newly privatized areas (Gillespie, 2007). Resident care aides, recreation, and facilities staff experienced a 15% wage rollback and layoffs (Lee & Cohen, 2005). For care aides at these facilities, who were primarily women of colour with limited financial resources, this meant having to do more with less, a challenge that likely contributed to high staff turnover rates in residential care facilities (Lee & Cohen; 2005; Stone & Dawson, 2008).

In, Out and About

Access to fields outside the facility represented a form of capital for many residents, but the ability of residents to enter these spaces was limited by accessibility and transportation issues. Zack pointed out: “[Several streets adjacent to the facility] don't have curb cuts,” which prevented him from going down them. Residents who could neither use regular public transport nor afford wheelchair taxis needed to contend with HandyDART, the local system for transporting individuals with disabilities. Hilda reported, “I don't like the HandyDART. [...] You have to phone two days ahead [for a booking], and [...] if [...] you're not [there] when they come and pick you up, it's too bad for you.” Although Vancouver has a reputation for being one of the world's most accessible cities, accessibility issues, previously documented in other settings (McClain, Medrano, Marcum, & Schukar, 2000; Meyers et al., 2002) often emerged, which suggest that there may be a distinction between accessibility and age friendliness of cities (World Health Organization, 2007) for residents who use wheelchairs. These environmental barriers represent a form of design apartheid (Imrie, 2001), in which residents who use wheelchairs are excluded from some spaces and discouraged from entering others. Kitchin (1998) suggests that

through these processes individuals are taught their value within society and those with disabilities are made to feel uncomfortable.

Power mobility was an important enabler of participation and independent outdoor mobility for residents. Whereas only two of the 11 manual wheelchair users went into the community independently, four of the five power wheelchair users were independently mobile outside the facility. Terrain was one of the biggest challenges for outside mobility. Ellen, who began the study using a manual wheelchair, commented, “I can take [my manual wheelchair] anywhere around [the facility] but if there is a steep grade that is impossible for me, I can go down, but coming up, that’s the problem.” Therefore, a power wheelchair, which has been noted to promote independent outdoor mobility in other populations (Auger et al., 2008), also allowed residents to inhabit fields outside the facility.

Power wheelchairs also provided residents with some unanticipated benefits, as Ellen later wryly observed,

When someone pushes me, other people tend to talk over me, to the person doing the pushing. But in the power chair people pay more attention to me, possibly because they are worried I might run them over.

In this situation, use of a power chair attracts additional capital, affording a shift in the power relations between Ellen and others, altering her status as a nonperson (Goffman, 1959) in those encounters.

As most participants were unable to leave the facilities independently in their wheelchairs, many occupied their time with facility-organized activities. Each care centre provided a structured recreation program, but programs were sometimes cancelled when activity staff were sick or on vacation because of limited backfill. Ellen observed, “Well, everybody goes on vacation [in the summer] and then [the activity workers] have to [...] do two jobs at the same time [because they don’t get replaced].” The programs offered did not meet the needs of all residents, and several participants described their lives as dull. Robert stated, “I am bored all the time.” The program Robert enjoyed attending, Casino night, attracted a large number of male residents but was only offered monthly. Both facilities had many Chinese residents and offered culturally sensitive programs facilitated by Chinese speaking volunteers and community groups. Despite these efforts, John, one of the recreation program leaders, noted, “it’s hard to make people who don’t speak very well in English understand what you’re trying to do.”

Boredom is a common problem that has been identified in residential care (Slama & Bergman-Evans, 2000; Thomas, 1994). A lack of suitable activities for male residents may explain why female residents have been reported to participate in more activities than their male counterparts (McGuinn & Mosher-Ashley, 2000). The difficulty accommodating residents from many cultures highlights some challenges associated with living and working in multi-cultural residential care facilities (Mold, Fitzpatrick, & Roberts, 2005).

Individuals with dementia, who were frequently confined to the facility in their wheelchairs, seemed the least engaged in facility based programs. James observed, “Residents with dementia are not self-entertaining [...] The[y] are just left [in the dining room] and what could be done? I don't know. You can't entertain these people constantly.” Perrin (1997) described this lack of involvement of residents with dementia as a form of deprivation.

For participants who could leave the facility, finances, an obvious form of capital, limited the places some went and the things that they could do. Two residents, both under 65 years of age, were on provincial disability assistance. They paid almost all of their monthly allowance directly to the facility leaving them with a small monthly income, as Hilda, a 63-year-old resident with arthritis, explained. “All I get is \$70 a month [...]” As these facilities were not all-inclusive, residents needed to pay a variety of out-of-pocket expenses for hairdressing, clothing, toiletries, and outings. As a result, one participant panhandled, “to help pay for cigarettes.” Poverty among residents has been noted as a concern for residents in other facilities (Diamond, 1992).

Meals were a very important aspect of facility life for residents. Although some residents were satisfied, many complained about the food. Residents who had the financial and mobility means could get food from outside the facility, as Ernie, who drove a power wheelchair, described. “Like today I didn't like lunch [...] so I went over to the mall [...] and bought myself a sandwich.” In these examples, it is evident that food, as a fundamental expression of habitus (Bourdieu, 1984), was one of the important kinds of comfort and capital in these settings.

Because of limited space in these settings and mobility issues among residents, issues of territoriality and privacy also arose. James noted that,

the television near the nurses station in the corner [...] always has a Chinese channel on it and there are probably four or five Chinese ladies or fellows that want to watch that... You don't go in there and change the channel or pretty soon in comes one of them and changes it back.

Private rooms were a much sought after capital that several participants wanted and that others had waited years to obtain. Rita explained, “My roommate has the TV on every day and very loud. I get very severe headaches from that kind of noise [...] and my husband doesn’t like to visit in my room, because he is sensitive to smells [when other residents are being changed].” Private rooms were more expensive, but they offered advantages of increased privacy and more control over immediate fields in which they lived. Despite the potential for conflict in common areas, we also observed residents helping one another. For example, residents who spoke multiple languages, like Gillian, an 80-year-old power mobility user, would translate for those who did not speak English.

Residents also shared spaces with staff members. At one point, staff and residents used to smoke together in a designated smoking area at one facility; but changes in provincial regulations meant that staff members were forced to smoke away from the facility buildings and grounds, which changed the shared smoking dynamic. Commenting on the new policy Henry stated, “I think it’s lousy. [The staff] got to go out on the street. They changed things. [...] We [used to] smoke together.” We observed many informal interactions in relation to smoking, including “bumming” cigarettes, lighting cigarettes, and chatting among fellow smokers. For some residents and staff at the beginning of the study, the smoking area represented a different and perhaps attractive field with less stringent rules and the opportunity to connect with others -- an ideal activity, disregarding the health risks, from the perspective of the Eden alternative that both facilities had adopted (Thomas, 1994). This social connection also offered residents the opportunity to establish relationships with staff – those who control access to most of the capital within these fields. Sharing spaces with staff also gave some residents the opportunity to monitor staff behaviour. From the position where she sat in her wheelchair, Ellen was able to observe staff leaving at the end of shift, and she said she would catch their eye and, “point at my watch if I s[aw] them leaving early.” This story represents a reversal of Bentham’s panopticon, in which the jailers become the ones who are watched, and is reminiscent of research that found, despite the surveillance they experience, residents are not passive agents in these facilities (Paterniti, 2003).

Summary and Implications

The residential facilities in this study represented grey spaces, where residents interact with each other, visitors, and staff. Contrary to research that has emphasized the dehumanizing aspects of residential life (Bland, 2007; Diamond, 1992; Fiveash, 1998; Vladeck, 1980), this

study found a wide spectrum of experiences among residents. The numbers of residents and the physical space of these facilities created an environment where residents need to compete with one another for finite resources. Their struggles in these contested, gendered, and ethnically diverse spaces were ongoing; and the outcomes were not always certain. That said, it was clear that residents with more capital and the appropriate habitus tended to be better able to get their needs met consistently. Wheelchairs represented a critical form of capital for residents as a means of obtaining other forms of capital and as an end to themselves in terms of their status, especially for power mobility users. The fields that residents could access inside and outside these facilities varied depending on the capital that each possessed and on the availability and allocation of wheelchairs in these settings.

Limitations of the study include the absence of non-English speaking interviewees, who represented a sizeable portion of residents at both facilities. Although an attempt was made to include residents whose first language was not English as part of the purposive sampling, the experiences of these English as a second language residents were likely quite different from residents who did not speak English. Therefore, we are limited in what we can say about non-English speaking residents from other cultures. Other residents that could not be included, except in general observations, were residents who were unable to provide their own consent and did not have family members who could provide consent to take part in the study. These residents with cognitive impairment and no family members were likely some of the most vulnerable individuals within these settings. Future research studies could include ethnographic studies that focused on subgroups that were not included in the current study.

Strengths of the research included the use of multiple qualitative methods and Bourdieu's conceptual framework. We found great value in being able to observe as well as to listen to residents who live in these settings and to contextualize those findings in terms of institutional policies and procedures. Bourdieu's framework was useful in exploring the relationship between the residents and the residential care environments in which they lived. Although, the term field is frequently applied to noncorporeal domains, such as academic disciplines, focusing on the residential care facilities as both concrete and epistemic objects afforded understandings about the importance of place and space among individuals within these fields.

The study suggests considering several practice, policy, and political changes. To address issues associated with the use of tilt-in-space wheelchairs and lap trays as unacknowledged restraints, outcomes produced, not intended use, could define restraint. As facilities purchase

new wheelchairs, resident propelled chairs could replace transport chairs. Policies to promote access to better equipment and power wheelchairs could potentially improve residents' mobility and community access. Employing transfer slings requires careful consideration. Removing barriers that discourage family involvement and creating private spaces for residents and their families to use will benefit such settings.

It seems counter-productive in light of the burgeoning cost of hospital care (Keehan et al., 2008), to expend substantial resources to keep people alive in hospital only to allow them live in substandard ways in residential care facilities in which they experience poor wheelchair equipment (Miller et al., 2004), poor staffing levels (Maas et al, 2008), and boredom (Slama and Bergman-Evans, 2000). Perhaps by providing better wheelchairs and additional care staff, secondary and tertiary prevention benefits would actually reduce rather than increase the overall costs associated with the complications of enduring substandard residential care. For example, although 4% of individuals in British Columbia live in residential care, one-quarter of those hospitalized with a femoral fracture from 1996 to 1999 resided in a facility (Ronald, McGregor, McGrail, Tate, and Broemling, 2008). It may be that better preventative programs could reduce the financial (emergency room, transportation and acute care) and personal costs associated with these injuries, especially given that some of these fractures may be restraint related (Neufeld, Libow, Foley, Dunbar, and Cohen, 1999). These changes would begin to address the overwhelming sense of scarcity in residential care (for residents and staff) that continues to make us as members of society complicit and/or silent except in the enterprise of doing more with less.

References

- Andrews, G.J., Cutchin, M., McCracken, K., Phillips, D.R., & Wiles, J. (2007). Geographical gerontology: The constitution of a discipline. *Social Science & Medicine*, 65, 151-168.
- Andrews, G.J., & Peter, E. (2006). Moral geographies of restraint in nursing homes. *Worldviews on Evidence-Based Nursing*, 3, 2-7.
- Auger, C., Demers, L., Gélinas, I., Juttai, J., Fuhrer, M.J., & DeRuyter, F. (2008). Powered mobility for middle-aged and older adults. Systematic review of outcome and appraisal of published evidence. *American Journal of Physical Medicine and Rehabilitation*, 87, 1-15.
- Bland, M. (2007). Betwixt and between: A critical ethnography of comfort in New Zealand residential aged care. *Journal of Clinical Nursing*, 16, 937-944.
- Bourdieu, P. (2000). Making the economic habitus: Algerian workers revisited. *Ethnography*, 1, 17-41.
- Bourdieu, P. (2001). *Masculine Domination* (R. Nice Trans.). Palo Alto, CA: Stanford University Press.
- Bourdieu, P. (1993). *Outline of a theory of practice* (R. Nice Trans.). New York: Cambridge University Press.
- Bourdieu, P. (1984). *Distinction: A social critique of the judgement of taste*. Cambridge, MA: Harvard University Press.
- Brienza, D.M., Karg, P.E., Geyer, M.J., Kelsey, S. & Trefler, E. (2001). The relationship between pressure ulcer incidence and buttock-seat cushion interface pressure in at-risk elderly wheelchair users. *Archives of Physical Medicine and Rehabilitation*, 82, 529-533.
- Capezuti, E., Brush, B.L., Won, R.M., Wagner, L.M., & Lawson, W.T. (2008) Least restrictive or least understood? Waist restraints, provider practices, and risk of harm. *Journal of Aging & Social Policy*, 20, 305-322.
- Castle, N.G., & Mor, V. (1998). Physical restraints in nursing homes: A review of the literature since the nursing home reform act of 1987. *Medical Care Research and Review*, 55, 139-170.
- Denzin, N.K., & Lincoln, Y.S. (2005). *Handbook of qualitative research*. Thousands Oaks, CA: Sage Publications.

- Diamond, T. (1992). *Making gray gold: Narratives of nursing home care*. Chicago, IL: University of Chicago Press.
- Edwards, C., & Imrie, R. (2003). Disability and bodies as bearers of value. *Sociology*, 37, 239-256.
- Fiveash, B. (1998). The experience of nursing home life. *International Journal of Nursing Practice*, 4, 166-174.
- Gaugler, J.E. (2005). Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health*, 9, 105-118.
- Gillespie, D.E. (2007). *The impact on organized labour of the health and social services delivery improvement act: A case study*. Master's degree thesis, University of Victoria. British Columbia. Retrieved December 12, 2008 from <https://dspace.library.uvic.ca:8443/dspace/handle/1828/1233>.
- Goffman, E. (1959). *The presentation of self in everyday life*. Doubleday Garden City, NY.
- Gubrium, J.F. (1975). *Living and dying at Murray Manor*. New York: St. Martin's Press.
- Harrington, C., Carrillo, H., & Blank, B.W. (2008). Nursing facilities, staffing, residents and facility deficiencies, 2001 through 2007. Department of Social and Behavioural Sciences, University of California, San Francisco, CA 94118
- Imrie, R. (2001). Barriered and bounded places and the spatialities of disability. *Urban Studies*, 38, 231-237.
- Kayser-Jones, J. (2002). The experience of dying: An ethnographic nursing home study. *The Gerontologist*, 42, 11-19.
- Kayser-Jones, J., Schell, E., Lyons, W., Kris, A.E., Chan, J., & Beard, R.L. (2003). Factors that influence end-life care in nursing homes: The physical environment, inadequate staffing, and lack of supervision. *The Gerontologist*, 43, 76-84.
- Keehan, S, Sisko, A. Truffer, C., Smith, S., Cowan, C., Poisal, J., Clemens, M.K., & the National Health Expenditure Accounts Projections Team (2008). Health spending projections through 2017: The baby-boom generation is coming to Medicare. *Health Affairs*, 27, w145-w155.
- Kitchin, R. (1998). "Out of place", "knowing one's place": Space, power and the exclusion of disabled people. *Disability & Society*, 13, 343-356.

Lee, M., & Cohen, M. (2005). *The hidden costs of health care wage cuts in BC*. British Columbia: Canadian Centre for Policy Alternatives BC Office.

Lynn, J., West, W., Hausmann, S., Gifford, D., Nelson, R., McGann, P., Bergstrom, N., & Ryan, J.A. (2007). Collaborative Clinical Quality Improvement for Pressure Ulcers in Nursing Homes. *Journal of the American Geriatric Society*, 55, 1663–1669.

Maas, M.L., Specht, J.P., Buckwalter, K.C., Gittler, J., & Bechen, K. (2008). Nursing home staffing and training recommendations for promoting older adults' quality of care and life: Part 1. Deficits in the quality of care due to understaffing and undertraining. *Research in Gerontological Nursing*, 1, 123-133.

Meyers, A.R., Anderson, J.J., Miller, D.R., Shipp, K., & Hoenig, H. (2002). Barriers, facilitators, and access for wheelchair users: Substantive and methodologic lessons from a pilot study of environmental effects. *Social Sciences and Medicine*, 55, 1435-1446.

McClain, L., Medrano, D., Marcum, M., & Schukar, J. (2000). A qualitative assessment of wheelchair users' experience with ADA compliance, physical barriers, and secondary health conditions. *Topics in Spinal Cord Injury Rehabilitation*, 6, 99-118.

McGuinn, K. K., & Mosher-Ashley, P. M. (2000). Participation in recreational activities and its effect on perception of life satisfaction in residential settings. *Activities, Adaptation and Aging*, 25, 77-86.

McIntosh, P. (1988). White privilege and male privilege: A personal account of coming to see correspondences through work in women's studies. *Working Paper No. 189*. Wellesley, MA: Center for Research on Women, Wellesley College.

Meyers, A.R., Anderson, J.J., Miller, D.R., Shipp, K., & Hoenig, H. (2002). Barriers, facilitators, and access for wheelchair users: Substantive and methodologic lessons from a pilot study of environmental effects. *Social Sciences and Medicine*, 55, 1435-1446.

Miller, W.C., Miller, F., Trenholm, K., Grant, D., & Goodman, K. (2004). Development and preliminary assessment of the measurement properties of the Seating Identification Tool (SIT). *Clinical Rehabilitation*, 18, 317-25.

Mold, F., Fitzpatrick, J.M., & Roberts, J.D. (2005). Minority ethnic elders in care homes: a review of the literature. *Age and Ageing*, 34, 107–113.

Morse, J.M. & Field, P.A. (1995). *Qualitative research methods for health professionals* (2nd ed.) Thousand Oaks, CA: Sage.

Mortenson, W.B., Miller, W.C., Boily, J., Steele, B., Odell, L. Crawford, E.M. & Desharnais, G. (2005). Perceptions of power mobility use and safety within residential facilities. *Canadian Journal of Occupational Therapy*, 72, 142-152.

Neufeld, R., Libow, L.S., Foley, W.J., Dunbar, J.M., Cohen, C., Breuer, B. (1999). Restraint reduction reduces serious injuries among nursing home residents. *Journal of the American Geriatrics Society*. 47, 1202-1207.

Paterniti, D.A. (2003). Claiming identity in a nursing home. In A.C. Gaw (Ed.), *Ways of aging* (pp. 58-74). Oxford: Blackwell Publishers Ltd.

Pekkarinen, L., Elovainio, M., Sinervo, T., Finne-Soveri, H., & Noro, A. (2006). Nursing working conditions in relation to restraint practices in long-term care units. *Medical Care*, 44, 1114-1120.

Perrin, T. (1997). Occupational need in severe dementia: A descriptive study. *Journal of Advanced Nursing*, 25, 934-941.

Phillips, C.D., Hawes, C., Mor, V., Fries, B.E., Morris, J.N., & Nennstiel, M.E. (1996). Facility and area variation affecting the use of physical restraints in nursing homes. *Medical Care*, 34, 1149-1162.

Reed-Danahay, D. (2001). 'This is your home now!': Conceptualizing location and dislocation in a dementia unit. *Qualitative Research*, 1, 47-63.

Reynolds, K., Hanson, L., DeVellis, R., Henderson, M., & Steinhauser, K. (2008). Disparities in pain management between cognitively intact and cognitively impaired nursing home residents. *Journal of Pain and Symptom Management*, 35, 338-396.

Ronald, L.A., McGregor, M.J., McGrail, K.M., Tate, R.B. & Broemling, A. (2008). Hospitalization rates of nursing home residents and community-dwelling seniors in British Columbia. *Canadian Journal on Aging*, 27, 109 – 115.

Sahyoun, N.R., Pratt, L.A., Lentzner, H., Dey, A., & Robinson, K.N. (2001). The changing profile of nursing home residents: 1985-1997. *Aging Trends*, 1-8.

Shaw, G. & Taylor, S.J. (1991). A survey of wheelchair seating problems of the institutionalized elderly. *Assistive Technology*, 3, 5-10.

Shields M. (2004). Use of wheelchairs and other mobility support devices. *Health Reports*, 15, 37-41.

Simmons, S. F., Schnelle, J. F., MacRae, P. G., & Ouslander, J. G. (1995). Wheelchairs as mobility restraints: Predictors of wheelchair activity in nonambulatory nursing home residents. *Journal of the American Geriatrics Society*, 43, 384-388.

Slama, C.A., & Bergman-Evans, B. (2000). Boredom, loneliness and helplessness. A troubling triangle. *Journal of Psychosocial Nursing*, 38, 37-43.

Smithers, J.A. (1990). A wheelchair society: The nursing home scene. *Journal of Aging Studies*, 4, 261-275.

Statistics Canada. (2007). Residential Care Facilities 2004/2005. Daily, Wednesday, May 30, 2007, residential care facilities.

Stone, R. I., & Dawson, S.L. (2008). The origins of better jobs, better care. *The Gerontologist*, 48, 5-13.

Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, CA: Sage.

Thomas, W. (1994). *The Eden alternative: Nature, hope and nursing homes*. New York: Eden Alternative Foundation.

Thorne, S., Reimer Kirkham, S. & MacDonald-Emes, J. (1997). Interpretive description: A non-categorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health*, 20, 169-177.

Trefler, E., Fitzgerald, S.G., Hobson, D.A., Bursick, T. & Joseph, R. (2004). Outcomes of wheelchair systems intervention with residents of long-term care facilities. *Assistive Technology*, 16, 18-27.

World Health Organization (2007). Global Age-Friendly Cities: A guide. Available at: www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf. Accessed May, 29, 2009.

Chapter 3: Factors Related to Mobility, Participation, and Quality of Life among Individuals in Residential Care Who Use Wheelchairs As Their Primary Means of Mobility. An Exploratory Qualitative Study ²

Many people who live in residential care facilities in North America rely on wheelchairs as their main means of mobility. Of the more than 150,000 Canadians and 1.5 million Americans over the age of 65 who live in residential care (He, Sengupta, Velkoff, & DeBarros, 2005), approximately half use a wheelchair as their primary way of moving about their facilities (Shields, 2004; Harrington, Carrillo & Blank, 2008). As the number of people 65 or older over is expected to double over the next 25 years (He, Sengupta, Velkoff, & DeBarros, 2005; Statistics Canada., 2005), the number of residents who use wheelchairs will likewise increase.

Appropriate wheelchairs can facilitate resident's mobility; however, the equipment that they receive is often unsatisfactory. Individually prescribed wheelchairs can significantly increase resident's propulsion speed (Trefler, Fitzgerald, Hobson, Bursick, & Joseph 2004). Unfortunately, wheelchair discomfort, immobility, poor posture, and dysfunctional wheelchairs are common problems that affect between 45% and 80% of residents (Fuchs & Gromak, 2003; Shaw & Taylor, 1991). Due in part to these equipment issues, Brechtelsbauer and Louie (1999) found that independent wheelchair mobility was minimal among residents. In contrast, in two facilities with good access to wheelchair equipment and prescription services, over half of residents were independently mobile (Bourbonniere et al., 2007).

Elements of the facility environment, including physical layout and institutional policies and practices also affect resident mobility. Earlier ethnographic studies have found that wheelchairs are sometimes used to restrain residents through the application of brakes that they cannot release (Gubrium, 1975; Smithers, 1990). Residents may also be prevented from accessing power mobility for safety reasons, which in turn limits independent mobility (Mortenson et al., 2005). Some residents in these settings are provided tilt-in-space wheelchairs (chairs with seats that can be tilted back while still maintaining the same angle between the seat and back). Such wheelchairs may increase comfort and positioning but may negatively affect mobility (Dewey, Rice-Oxley, & Dean, 2004).

²A version of this chapter will be submitted for publication. Mortenson, W.B., Miller, W.C., Oliffe, J.L., & Backman, C.L. Title: Factors related to mobility, participation and quality of life among individuals in residential care who use wheelchairs as their primary means of mobility. An exploratory qualitative study.

Research has identified a lack of purposeful activity as a serious problem among residents, including wheelchair users. Observational studies have found that residents are offered little or no activity (Gottesman & Bourestom, 1974; Ice, 2003, Voelkl, Winkelhake, Jeffries, & Yoshioka, 2003; Ice, 2002), and this problem is especially evident among residents with dementia (Perrin, 1997). For residents who use wheelchairs in the community, participation issues are compounded by discrimination (Mortenson et al., 2005).

Quality of life has also been identified as an area of concern for individuals in residential care in nonwheelchair specific research. Observational studies suggest residents with dementia experience decreased well-being (Chung, 2004; Perrin, 1997). The dehumanizing aspects of residential care facilities are well-documented (Fiveash, 1998; Kayser-Jones, 1981; Vladeck, 2003), and it has been proposed that the current model of care provision of these institutions is associated with poor quality of life for residents (Kane, 2003).

Given the prevalence of wheelchair use in residential care facilities and difficulties encountered by residents in these settings, we conceived a study to identify the most important predictors of mobility, participation, and quality of life for residents who use wheelchairs as their primary means of mobility, with the aim of identifying areas suitable for future intervention.

When planning quantitative studies, researchers must select from a wide variety of potential variables. Although variables can be identified based on conceptual models or previously published research, identifying the most important variables, especially in light of issues of sample size and power, can be a challenge. For example, the Matching Person to Technology (MPT) model (Scherer, 1998; see page 92), a contemporary and commonly used model of assistive technology (Lenker & Paquet, 2003), indicates that successful outcomes of assistive technology prescription require careful consideration of the characteristics of the user, their environment, and the type of assistive device. Although the MPT is useful as a generic model, it does not provide an indication of which characteristics of these domains are most relevant for individuals living in a particular setting using a specific type of assistive technology. As qualitative inquiry has been suggested by Barbour (1999) as a good method of identifying relevant variables for quantitative research, we conducted a qualitative study to populate the MPT model by identifying nondemographic factors that enable the 1) mobility, 2) participation, and 3) quality of life of residents who use wheelchairs as their primary means of mobility.

Methods

We used an ethnographic, multi-method approach (Teddlie & Tashakkori, 2003), which included a series of two or three participant observations sessions with residents from two facilities and a similar number of in-depth interviews with either the resident or a family member/surrogate if the resident was not competent to consent to an interview. The study protocol was approved by the local university ethics board as noted in Appendix 2.

Eligibility and Recruitment

To be included in the study, residents, either independently or with the assistance of others, needed to use a wheelchair as their main means of mobility (to get from their bed to the common room on their ward). Participants either needed to speak English or, if the resident was not competent to provide consent, have a family member who could. We purposefully recruited participants for maximum theoretical variation in terms of whether they 1) were independent or dependent with mobility, 2) used their wheelchairs inside and outside the facility, 3) had cognitive impairment, 4) spoke English as a second language, and 5) used power, standard manual wheelchairs, or tilt-in-space wheelchairs. Residents or their surrogate decision makers were invited to take part in the research by a neutral third party at each facility. Assent was obtained from residents who were not competent to provide informed consent and surrogate decision makers provided consent. Posted notices indicated that participant observations were underway when observations were conducted. We asked staff and family members for their consent before including them in observations; and we asked non-study residents interacting with study residents for their assent or consent, as it was not possible to determine which residents were competent to provide consent during these observations.

Facilities

Table 3.1 provides summary information about the similarities and differences between the facilities. Facility 1 had better wheelchair resources and a lower resident/occupational therapy staffing ratio: professionals who devoted a large part of their time to wheelchair prescription, training, and ongoing monitoring of residents in their wheelchairs.

Data Collection

Interviews lasted 60 minutes on average, ranged between 30 and 120 minutes, and we structured them based on a series of evolving interview guides. In the first round of interviews, we asked residents and family members to describe a typical day. This was followed up with questions about what activities wheelchairs helped or hindered residents from performing,

experiences they had using their wheelchairs inside and outside the facility, kinds of assistance residents required; quality of assistance residents received, activities residents participated in, frustrations they encountered, and things they enjoyed. Subsequent rounds of interviews began by asking participants to describe any resident, wheelchair or facility changes that had occurred since the preceding interview. We followed up responses with probes about these changes and topics that required further exploration from within or across previous participant interviews. We completed member checking as part of the last round of interviews, during which the main preliminary findings of the research were presented back to all participants for their comments and feedback.

With most residents or family members, we conducted three in-depth interviews; however, two family members who were acting as surrogates were unavailable for a third interview. Interviews were audio recorded and transcribed verbatim. Following interviews, we wrote fieldwork notes that described the content of the interview, nonverbal behaviour, impressions, and impact of the investigator on the research process (Hammell, Carpenter & Dyck, 2000).

Participant observations lasted two to four hours and we conducted them using an observation guide that recorded the places residents went inside and outside the facility, how they got there (self-propelled or pushed), the things they did in their wheelchairs, interactions that they had, and any barriers or facilitators they encountered. Interviews and participant observations were carried out by the first author or one of two trained Master's students.

Participants

Sixteen residents, eight from each facility, participated in repeated observations. These included eight men and eight women with an average age of 81 years ($SD=11.3$, range 55-96) who had lived in the facility from three months to four years ($M=1.7$ years, $SD=1.1$) and had between six months and 52 years of wheelchair experience ($M=5.9$ years, $SD=12.6$). Ten participants used manual wheelchairs, including three tilt-in-space chairs, five participants used power mobility, including three power tilt-in-space wheelchairs that enabled them to tilt independently, and one participant used a power and a manual wheelchair. Six participants spoke English as a second language, including three Chinese speakers. Residents had a variety of diagnoses (number of participants indicated in parenthesis) including dementia (3), stroke (2), spinal cord injury (2), arthritis (4), diabetes (8), macular degeneration (4), osteoporosis (1) and trauma (1). Four family members and one paid companion acted as informants for five residents

who were not competent to provide their own consent. Additionally, two family members of self-responding residents took part in one-off interviews.

Data Analysis

Data collection and analysis was an iterative process that was ongoing throughout the research process (Hammersley & Atkinson, 1995). First, we reviewed transcripts to identify instances of mobility, participation, and quality of life among residents. For this process, we considered mobility to represent displacement from one location to another, and we defined participation as the activities that residents did inside and outside their facilities. We conceptualized quality of life as the subjective evaluations that residents made about their lives in relation to their goals, expectations, and concerns (World Health Organization, 1997) or similar assessments made by family members of residents who were not competent to provide their own consent. By reading and re-reading the interview transcripts, and observations and interview notes, we identified the most salient factors that contributed to these instances of resident's mobility, participation, and quality of life and developed an initial coding scheme that evolved over the course of the analysis. We clarified contributing factors in subsequent interviews and further explored them in ensuing observations to refine this coding scheme and eventually to develop a final coding scheme that we applied to all the data (Morse & Field, 1995). For many mobility, participation, and quality of life outcomes, we identified multiple contributing factors.

To determine the relative importance of each of these codes, we counted the number of documents (interviews and participant observations) in which we identified these codes. If we noted that a code appeared multiple times in the same document, that document was only counted once (i.e., there was no weighting for the frequency with which that code appeared in the document). This count was divided by the total number of documents (n=92) to calculate a percentage, which represented approximately six documents per resident. We selected quotes to illustrate each of these factors, and categorized them into the person, technology and environmental domains of the Matching Person to Technology Model (MPT) of assistive technology (Scherer, 1998)

Trustworthiness Strategies

We used triangulation and member checking as trustworthiness strategies. The inclusion of residents and family members, the use of multiple researchers and repeated interviews and observations were forms of triangulation used to extract a variety of potentially divergent

perspectives on the topic (Morgan-Ellis et al., 2006). With triangulation, we anticipated we would develop a more complete understanding of the topic under investigation. We used member checking to determine how well the investigators' interpretations reflected the participants' perceptions (Morrow, 2005). During member checking, we described four preliminary themes that encompassed most of the factors identified and reviewed a conceptual diagram indicating the relationship between resident's mobility, participation, quality of life, and environmental factors (described in Appendix 4). We provided residents with relevant examples to illustrate how their data was reflected in the themes and model. We asked participants to comment on how the themes and the conceptual model resonated with them. Generally, participants indicated that the themes and model were reflective of their experiences within their facilities.

Results

There were a wide range of factors related to mobility, participation, and quality of life outcomes among participants, which we present in three tables. In each table, we list factors in decreasing frequency according to the domains of the MPT. We indicated illustrative quotes with quotation marks, whereas notes from participant observations are without bracketing punctuation.

Mobility

We describe factors related to the mobility of participants in Table 3.2. In terms of personal factors, physical ability, which included concepts such as ability to transfer, vision and health, was the most frequently identified factor associated with mobility. Finances, another personal factor, influenced the type of wheelchair residents received, especially at Facility 2, which had fewer wheelchair-related equipment and personnel resources. In terms of environmental factors, institutional characteristics, including equipment or furniture that cluttered hallways and prevented residents from moving about freely (example in Table 3.1), were the most frequently identified environmental issues that affected mobility. In terms of technological factors, we identified wheelchair skills (which included both personal and technological elements) in over half of the interviews and observations as factors that affected mobility. As noted in the illustrative quote for this factor, one resident could be immobilized in her wheelchair, because staff could apply brakes that she did not know how to release (an example that included environmental and personal elements). Having an appropriate wheelchair that was easy to move, for example, was related to mobility in over half of all interviews and participant observations. Wheelchair confidence was a novel factor that was associated with

mobility. This factor included residents' beliefs about their ability to propel their wheelchairs and observations in which residents used their wheelchairs in a self-assured manner in potential dangerous or difficult situations, such as going down steep hills, negotiating parking lots, or entering and exiting crowded elevators.

Participation

We describe factors related to participation among residents in Table 3.3. The personal, environmental, and technological factors that we most frequently related to participation — physical ability, institutional factors, and wheelchair appropriateness respectively — were the same factors that participants associated with mobility; however, the specific institutional elements we identified were different. For example, limited weekend recreational staffing decreased opportunities for participation for some residents. Many of factors that were associated with mobility were also associated with participation outcomes among participants, but we also identified three additional participation factors. Cultural appropriateness, a term used to describe when activities matched the dominant cultural ideals of particular residents, was an environmental factor that we noted in one-quarter of documents, especially among residents who spoke English as a second language. For Chinese speaking residents, culturally appropriate activities included eating Eastern cuisine and having the opportunity to take part in activities like Tai Chi and playing games including Mah Jong. We noted depression, a personal affective factor, interfered with participation in 10% of documents. We identified mobility itself as an additional potential enabler of participation, because, as a participant pointed out, without an appropriate wheelchair he would be confined to bed, which would curtail his involvement in activities. We presented this factor outside the MPT model, as it represented an outcome that resulted from an interaction among factors from all three MPT domains. Finances could also limit participation for some residents who could not afford to take part in some activities.

Quality of Life

We describe factors related to quality of life among participants in Table 3.4. Although many of the factors were similar to those that were associated with mobility and participation, the quality of life factors focused on the residents' evaluations of elements of their lives. Generally, the frequency of quality of life factors identified by participants was lower than the frequencies for mobility and participation outcomes. Residents described factors affecting their mobility and participation more often than they commented on their satisfaction with elements of their lives. The most frequently identified personal factor was pain, an issue that was related to

quality of life in approximately one-quarter of observations and interviews. As with mobility and participation, institutional factors were the most common environmental factors. Wheelchair satisfaction was the only technological factor that was associated with quality of life. Satisfaction with mobility and, more importantly, satisfaction with participation were two additional factors that residents indicated and participant observations suggested were related to their quality of life. Once again, we presented these factors outside the MPT, as they also represented outcomes of wheelchair use.

Discussion

We used these qualitative data to identify a variety of factors related to mobility, participation, and quality of life outcomes among residents who use wheelchairs as their primary means of mobility and who live in two residential care facilities. Some of these factors are similar to those identified in empirical research with residents who were not specifically wheelchair users; however, we inductively derived some additional novel variables for this population.

The mobility findings of the current study are generally consistent with those from the small number of studies in this area. For example, Bourbonniere and colleagues (2007) found the only significant predictor of the extent to which residents moved throughout their facility was their need for wheelchair intervention to address problems such as sliding, leaning, pressure areas or difficulty propelling. Institutional factors such as hallway clutter and lack of staffing to assist residents who could not self-propel have been identified as barriers to mobility in previous qualitative research (Mortenson et al, 2005). Facility practices, such as the application of brakes that residents cannot release, which have previously been documented (Gubrium, 1975; Smithers, 1990) continue to be an issue in these settings. Accessibility problems encountered by residents using power mobility (Mortenson et al., 2005) also appear relevant for those who use manual wheelchairs in these settings. Although many of the other factors identified are intuitively appealing, most have not previously been linked empirically with mobility among facility residents. Finances, for example, likely contributed to wheelchair appropriateness and ultimately mobility among some participants, especially those at Facility 2. Wheelchair mobility confidence was a novel factor and an important enabler of mobility for some participants, especially in terms their power wheelchair use and travel outside the facility. To date, the only research that has examined wheelchair confidence was a study by Hoenig et al. (2005) that found that expert provision of manual chairs had no effect on wheelchair confidence; however,

wheelchair confidence was measured using an un-validated, single-item, study specific measure. As a form of self-efficacy (Bandura, 1977), a relationship between mobility and wheelchair mobility confidence would be anticipated.

Our findings reflect results from nonwheelchair-user-specific studies that have explored the predictors of participation among individuals in residential care. Cognitive factors (Chung, 2004; Kolanowski, Buettner, Litaker, & Yu, 2006; Voelkl, Fries, & Galecki, 1995); depressive affect (Voelkl et al., 1995); physical ability in the form of functional ability (Kolanowski et al.; Schroll, Jonsson, Mor, Berg, & Sherwood, 1997) and sensory impairment (Resnick, Fries, & Verbrugge, 1997); communication (Resnick et al, 1997); pain (Cadogan et al., 2008); institutional factors (Ice, 2002; Thomas, 1994; Voelkl, Winkelhake, Jeffries, & Yoshioka, 2003) and assistance of families (Gaugler, 1995) have been associated with participation in previous studies. It also seems likely that residents who use their wheelchairs in the community encounter similar discriminatory practices that limit the participation of community-dwelling individuals who use wheelchairs (Cahill & Eggleston, 1995; McClain., Medrano, Marcum, & Schukar, 2000; Meyer et al., 2002). We identified two novel residential-care participation factors in this study: finances and culturally appropriate activities. Finances are a particular concern for low-income residents, as these facilities are not all inclusive and residents are expected to pay for a variety of out of pocket expenses, which usually includes the price of admission and cost of meals during outings (Harris, 2005). The identification of cultural appropriateness as a factor was likely the result of our purposeful sampling of residents whose first language was not English. The prevalence of non-English speaking residents in these facilities raises a potentially serious concern; as such residents may become isolated in these settings if familiar/culturally appropriate opportunities for social participation are not available (Mold, Fitzpatrick, & Roberts, 2005). This is particularly important since population projections indicate that, by 2017, the majority of people living in the Vancouver metropolitan area will be from what are currently labeled as “visible minorities” (Statistics Canada, 2005).

The mobility and participation factors we identified lend empirical support to the relational model of wheelchair mobility proposed by Routhier and colleagues (2003) and suggest the model could be applied to residents living in long-term care. According to this framework, wheelchair mobility, which ultimately leads to social participation, results from an interaction among five constructs: attributes of the wheelchair user, the wheelchair, wheelchair assessment and training, the physical and social environment, and the daily activities and the social roles that

the individual engages in. All of the factors identified in the current study, with the exception of weather and comfort, are named explicitly within the Routhier relational model of wheelchair mobility. In this regard, the use of a device-specific model may offer a more refined conceptual understanding of wheelchair mobility outcomes; but, given the large number of factors identified in the relational model, it remains a challenge to determine which factors are most important for research and assessment purposes.

Some factors associated with quality of life in the current study have previously been documented in nonwheelchair-specific research. Quality of life has been associated with cognition (Chung, 2004; Edelman et al., 2005), functional ability (Edelman, Fulton, Kuhn, & Chang, 2005; Patrick, Kinne, Engelberg, & Pearlman, 2000), self-perceived health (Patrick et al., 2000), participation in self-generated activities (McGuinn & Mosher-Ashley, 2000), perception of personal control (Duncan-Meyers & Huebner, 2000), perceived staff support of resident autonomy (Kasser & Ryan, 1999), perceived family support of resident autonomy (Kasser & Ryan), and depression (Patrick et al., 2000).

The relationship between some factors identified in this study and quality of life are not well studied among those living in residential care. A link between pain and quality of life for this population has been suggested by Zanolchi et al. (2007), but this association was not studied empirically. In terms of the importance of the institutional environment, some research that staff training, favourable staff attitudes and better resident-staff communication is related to better quality of life of resident among residents with dementia (Zimmerman et al., 2005). The adoption of the Eden philosophy, as an alternative, more humanistic mode of care, has also been associated with decreased boredom and helplessness among residents (Bergman-Evans, 2004). It has also been suggested that limited finances may contribute to negative quality of life (Diamond, 1992; Harris, 2005). Though not specific to residential care, some quantitative studies have suggested a link between wheelchair use and quality of life. Devit and colleagues (2003) found that individuals with multiple sclerosis who used a wheelchair daily had better quality of life scores. Davies, De Souza, and Frank (2003) found individuals who received a power wheelchair had significantly improved health-related quality of life. The importance of other residents, which is related to sharing a room, is not unexpected, given the difficulties associated with communal living noted in these settings (Hauge & Heggen, 2006). Previous research by Kane et al. (1997) found 56% of residents surveyed reported that it was very important to have choice and control regarding roommate selection. Factors such as finances and accessibility,

societal issues, which have not been previously been associated with quality of life for this population, suggest an opportunity for future research in this area.

As depicted in Figure 3.1, a modified version of the MPT model, our findings suggest there is an interaction among mobility, participation, and quality of life outcomes for residents. According to our model, different objective and subjective elements of personal, wheelchair, and environmental factors contribute to mobility, participation, and quality of life outcomes. Although some direct influence of wheelchair factors on participation and quality of life outcomes (indicated via more lightly shaded curved arrows) is possible, based on our findings we propose that wheelchair-related factors variables will primarily have direct effects on mobility, which in turn influences participation and ultimately life satisfaction. For example, if a resident's power wheelchair breaks down, he may be stuck in bed (reduced mobility), which will have a direct effect on his participation that will likely alter his quality of life. This model is similar to the quality of life model proposed by Post, de Witt, and Schrijvers (1999), which predicts a linear relationship between functional issues, participation, and quality of life; however, our model makes the influence of wheelchair-related factors, and mobility more explicit.

Strengths and Limitations

One of the benefits of this study is that it offers the possibility of identifying novel factors that might not be found in a search of the literature or by using conceptual models. This is especially important as the factors that were relevant may change over time due to macro-environmental changes like immigration and economic crises. In this regard, longitudinal data collection over several months and multiple methods were strengths of the study. Purposeful sampling is beneficial from a qualitative perspective; however, the frequency with which factors were associated with various outcomes would likely be different if a random sample of residents was studied. As well, although the frequency of these potential factors was calculated, this percentage does not necessary indicate the strength of the relationships between these constructs. For example, the number of times pain was mentioned by participants does not reflect the severity of pain they experienced, which may have a more important impact on mobility, participation and quality of life outcomes. Finally, the current study combines data from residents with and without cognitive impairment; and the potential exists that possible factors may vary in each subpopulation.

As a method of variable selection, this qualitative process enabled the identification of novel factors that might not have been considered in relationship to mobility, participation, and quality of life outcomes. This method of data collection was time-consuming. Other approaches, such as the use of a nominal group or Delphi panel, may have been more efficient; but these approaches would have excluded more residents from participating, given their increased complexity.

Conclusion

This study reveals factors that were associated with mobility and participation and quality of life among residents in two facilities. Future studies could look at factors related to these outcomes in privately funded institutions or in facilities in other jurisdictions with different funding systems and could use different qualitative methods. This study lays the groundwork for future research in this area by identifying potential factors that could be further explored using qualitative or quantitative methods of inquiry. The results may also have relevance for residents living in similar settings in other jurisdictions. In preparation for the quantitative phase of the study, variables identified in this qualitative phase of the study were prioritized and appropriate measures to capture these variables were selected as described in Appendix 5.

Table 3.1: Differences and Similarities between Facilities Studied

Similarities	Differences ^a	
Facility 1 & 2	Facility 1	Facility 2
<ul style="list-style-type: none"> • @200 bed • @40% Chinese speakers • >90% use wheelchairs as primary means of mobility • Government funded • 50% with dementia 	<ul style="list-style-type: none"> • @1 occupational therapist per 80 residents • Most wheelchairs and seating provided by facility • More urban 	<ul style="list-style-type: none"> • @1 occupational therapists per 160 residents • Residents encouraged to purchase non-basic wheelchairs • More suburban

a = only limited descriptive data can be included to protect the identity of facilities in the study

Table 3.2: Mobility Factors, Percentage of Documents in Which These Variables Were Identified, and Examples

Factors	%	Mobility Quotes and Observations
Personal		
Physical ability (transfers, vision, health)	62	“They had adjusted the wheelchair to see if there was some way that she could start maneuvering herself [...], but she hasn't got enough control with the hand that works [after her stroke]
Cognition (problem solving, memory, visual perceptual, route finding)	30	Residents who wander have a radio frequency identification tag installed on their chairs that stops the elevators and prevents them from leaving their floor
Finances (income)	30	“[My power wheelchair] cost \$13,000. I buy it myself. Nobody help.”
Communication (reception and production)	12	“He has a problem voicing his opinion, he can't say, ‘No, I'm not going to go here.’ ”
Pain (intensity, interference)	10	“It's very difficult pushing this [manual wheelchair because I broke my shoulder in...] one of my falls [...]and it's still sore.”
Environmental		
Institutional factors (crowding, hallway clutter, availability of equipment, staffing, and training)	76	The resident went towards the side of her bed, but her way was blocked by a chair, which had been left out by one of the staff.
Accessibility (automatic doors, level thresholds, elevators, narrow aisles)	47	“Sometimes the [doorway threshold] is not quite even [...and someone] has to give me a shove.”
Societal factors (discrimination, funding, transportation, assistance from public)	40	“I don't like [our transport system for people with disabilities, because you have to phone ahead] two days, and then [...]if you're not there [on time] when they come and pick you up, it's too bad for you. You can stay there.”
Assistance of family and friends (pushing and assisting transfers)	26	“If I'm here, usually I will push [my mother], if we're going to go from one [room] to the other.”

Factors	%	Mobility Quotes and Observations
Natural environment (hills, rain, snow)	25	“I could wheel myself around, up hills a bit. [...] But if they are too steep, I need a push.”
Technological		
Wheelchair skills (independent propulsion, operating brakes, etc.)	62	Because one resident didn't know how to release her own brakes, “[Staff] could put the breaks on and keep her in one spot.”
Wheelchair appropriateness (comfort, set up for independent propulsion, positioning in chair, power mobility)	60	“[My new wheelchair] moves a little easier than the old one. It's not as wide, it's not as big.”
Wheelchair confidence (self-efficacy regarding wheelchair mobility)	16	“When I have a small manual chair [...] I'm confident in what I'm doing. Whereas the electric chair is bigger and I find [...] I put more restraints upon myself. I'm not as comfortable. I think I'm not quite as in control as I am with the manual.”

Table 3.3: Participation Factors, Percentage of Documents in Which These Were Identified, and Examples

Factors	%	Participation Quote and Observations
Personal		
Physical ability (transfers, vision, hearing, health)	63	“I can get out of my chair to go to the toilet. I can transfer myself onto the bed.”
Finances (income)	51	“I’m on [disability assistance], so they take all my pension and give me \$95.00 back a month, which makes it hard to pay for smokes”
Communication (reception and production)	33	“[The language barrier] is really hard [... for those residents who don’t speak English]. They’re very frustrated when they can’t tell me what they want, or ask me something.”
Pain (interference and intensity)	15	“It’s hard to do things when you are sore all over and aching. The arms. I am sore at every joint, so I get my pain killers. It wears off a bit, but never ceases.”
Cognition (problem solving, memory, visual perceptual, route finding)	14	“[My mother didn’t go to the church service]mainly because she didn’t [...] understand what it was and she just says no automatically.”
Affect (depression)	10	“You get depressed and then you can’t sleep.”
Environmental		
Institutional factors (staffing, recreational programming, training)	84	“[On] the weekend there’s not really any activity here because the [recreation] staff is [...] not here.”
Assistance of family and friends (help with participation)	58	“My sister and I take [my father] out for dinner or lunch and we take him down to the race tracks because he loves gambling.”
Accessibility (automatic doors, level thresholds, elevators, narrow aisles)	26	“My son had a barbeque party, [but I wasn’t] able to get in to his place [because he has stairs].”
Cultural appropriateness (consistent with cultural	26	Christmas dinner consisted of turkey, stuffing and a variety of Chinese dishes

Factors	%	Participation Quote and Observations
preferences)		
Societal Factors (discrimination, funding, transportation, assistance from public)	23	“I went in to the dollar store, however I couldn't reach the [thing] I wanted and so there was a young girl [who] got it for me.”
Natural environment (hills, rain, snow)	15	“We were going to take my dad [out to eat] today if it was a nice day but they've been calling for rain all day and I don't want to [in those conditions].”
Technological		
Wheelchair appropriateness (comfort, set up for independent propulsion, positioning in chair)	39	“If she didn't have [a tilt in space wheelchair...], she wouldn't have been able [...to go to] the symphon[y] [or go] shopping.”
Other		
Enabled by mobility	28	“Nice to have a good wheelchair to get around in, otherwise I'd be stuck in bed.”

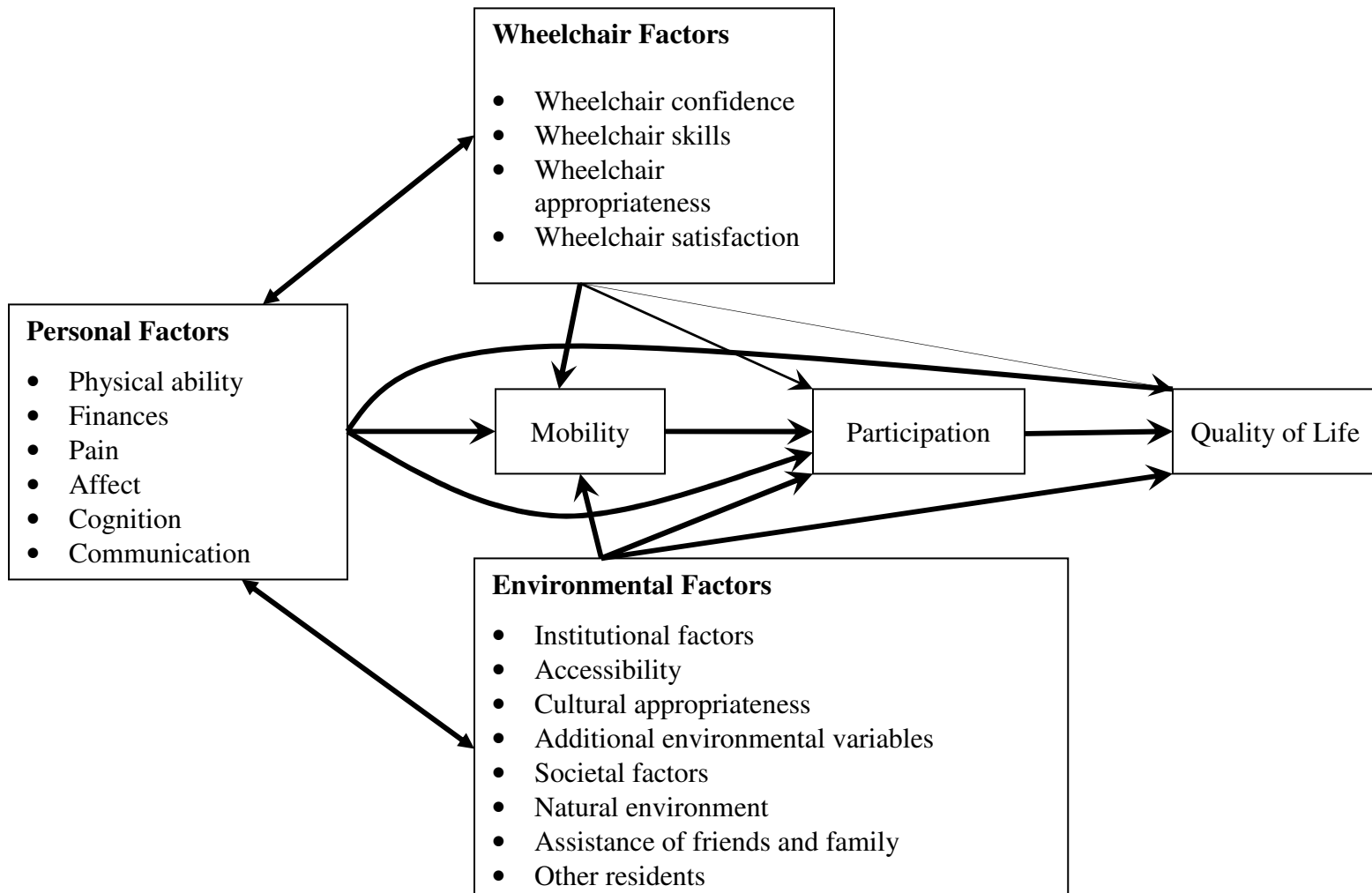
Table 3.4: Quality of Life Factors, Percentage of Documents in Which These Were Identified, and Examples

Factors	%	Quality of Life quote and observations
Personal		
Pain (intensity and interference)	26	“I’m in enough pain already. I don’t want to go through no more.”
Physical ability (satisfaction with ability to move wheelchair, transfer, vision, hearing, health)	22	“I cannot see too well. You know macular Degeneration? [...]I was crocheting so very much [...] I cried when I could not see [anymore].”
Finances (satisfaction with income)	22	“I either have to stay here, or win the jackpot or something.”
Control (satisfaction with degree of control)	17	“It’s a big jump from being very independent to not being able to do anything at all.”
Cognition (comprehension, memory)	10	“She doesn’t understand why she is where she is. She says, ‘I can’t wait to get out of here.’”
Communication (reception and production)	10	“When a staff tells them, ‘You have to wait,’ they may not understand. They may think, “No.” They may say something that [the staff] don’t understand or they get frustrated.”
Affect (depression)	10	“Every time the people he interacts with leave [or pass away...] it sort of sets in a depression.”
Environmental		
Institutional factors (satisfaction with institutional environment in terms of crowding, availability of equipment, staffing, recreational programming, and training)	66	“One of the staff is quite uplifting. I call her my sunshine. [...] She is happy all the time.”
Other residents (Satisfaction with others excluding room-mates)	52	“The opportunities for friendship are definitely restricted. That’s one of the problems here.”
Assistance of family and friends (satisfaction with assistance from family and friends)	43	“A lot of [residents] don’t have families that come in and see them. It’s sad to see someone so lonely.”

Factors	%	Quality of Life quote and observations
With or without room mates (Satisfaction with/without room mates)	35	She tells me she want a private room so she can have more space and it will be quieter and not as smelly when they are changing her room mates.
Societal factors (satisfaction with funding, transportation, assistance from and attitudes of public)	18	“If you have someone with you and [...] you’re in a store or in a restaurant [...] they talk over your head as if you’re invisible or you’re mentally incapable.”
Natural environment (satisfaction with terrain, weather, gardens etc.)	18	“[The garden is] beautifully done. [...]. It’s a little Garden of Eden for them. They love that.”
Accessibility (satisfaction with accessibility)	14	“The cobblestones would cause a great deal of anxiety on my part. I probably would crash.”
Cultural appropriateness (satisfaction with cultural appropriateness of activities)	9	One participant’s family brought in food for him daily because he could not eat the Western cuisine
Technological		
Wheelchair satisfaction (comfort, set up for independent propulsion, positioning in chair)	29	“Often I spend my days in [my power wheelchair] because [...] I can tilt it back and relax [...] and listen to music.”
Other		
Enabled by mobility satisfaction	13	“What she likes is to be taken around slowly. [...]If we are out and it’s a nice day she can just sort of feel the sensations around her and see things.”
Enabled by participation satisfaction	47	“The stroke was quite devastating because he was [so] active [before].”

Figure 3.1

Modified Matching Person to Technology Model



References

- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behaviour change. *Psychological Review*, 84, 191-215.
- Barbour, R.S. (1999). The case for combining qualitative and quantitative approaches in health services research. *Journal of Health Service Research and Policy*, 4, 39-43.
- Bergman-Evans, B. (2004). Beyond the basics. Effects of the Eden Alternative model on quality of life issues. *Journal of Gerontological Nursing*, 30, 27-34.
- Bourbonniere, M.C., Fawcett, L.M., Miller, W.C., Garden, J., & Mortenson, W.B. (2007). Prevalence and predictors of need for seating intervention and mobility for persons in long-term care. *Canadian Journal on Aging*, 26, 195-204.
- Brechtelsbauer, D. & Louie, A. (1999). Wheelchair use among long-term care residents. *Annals of Long Term Care*, 7, 213-20.
- Cadogan, M.P., Edelen, M.O., Lorenz, K.A., Jones, M., Yosef, J., Hascall, T., Simon, B., Harker, J.O., Ferrell, B., & Saliba, D. (2008). The relationship of reported pain severity to perceived effect on function of nursing home residents. *Journal of Gerontology*, 63A, 969-973.
- Cahill, S.E. & Eggleston, R. (1994). Managing emotions in public: The case of wheelchair users. *Sociological Quarterly*, 57, 300-312.
- Chung, J. C. C. (2004). Activity participation and well-being in people with dementia in long-term care settings. *Occupational Therapy Journal of Research*, 24, 22-31.
- Davies, A., De Souza, L. H., & Frank, A. O. (2003). Changes in the quality of life in severely disabled people following provision of powered indoor/outdoor chairs. *Disability and Rehabilitation*, 25, 286-290.
- Dewey, A., Rice-Oxley, M., & Dean, T. (2004). A qualitative study comparing the experiences of tilt-in-space wheelchair use and conventional wheelchair use by clients severely disabled with multiple sclerosis. *British Journal of Occupational Therapy*, 67, 65-74.
- Devitt, R., Chau, B., & Jutai, J. W. (2003). The effect of wheelchair use on the quality of life of persons with multiple sclerosis. *Occupational Therapy in Health Care*, 17, 63-79.
- Diamond, T. (1992). *Making gray gold: Narratives of nursing home care*. Chicago, IL: University of Chicago Press.
- Duncan-Myers, A. M., & Huebner, R. A. (2000). Relationship between choice and quality of life among residents in long-term-care facilities. *American Journal of Occupational Therapy*, 54, 504-508.

Edelman, P., Fulton, B. R., Kuhn, D., & Chang, C. H. (2005). A comparison of three methods of measuring dementia-specific quality of life: Perspectives of residents, staff, and observers. *The Gerontologist*, 45 Spec No 1, 27-36.

Fiveash, B. (1998). The experience of nursing home life. *International Journal of Nursing Practice*, 4, 166-174.

Fuchs, R.H. & Gromak, P.A. (2003). Wheelchair use by residents of nursing homes: Effectiveness in meeting positioning and mobility needs. *Assistive Technology*, 15, 151-163.

Ghusn, H. F., Hyde, D., Stevens, E. S., Hyde, M., & Teasdale, T. A. (1996). Enhancing life satisfaction in later life: What makes a difference for nursing home residents. *Journal of Gerontological Social Work*, 26, 27-47.

Gubrium, J.F. (1975). *Living and dying at Murray Manor*. New York: St. Martin's Press.

Hammell, K.W., Carpenter, C. & Dyck, I. (2000). Using qualitative research. A practical introduction for occupational and physical therapists. New York: Churchill Livingstone.

Hammersley M. & Atkinson, P. (1995). *Ethnography. Principles in practice* (2nd ed). New York: Routledge.

Harris, J. (2005). *Uncovering the cost of care: An examination of extra billing in BC's long-term care facilities*. Master's thesis, Simon Fraser University. Burnaby.

Hauge, S., & Heggen, K. (2007). The nursing home as a home: A field study of resident's daily life in the common living rooms. *Journal of Clinical Nursing*, 17, 460-467.

Herrington, C., Carrillo, H., & Blank, B.W. (2008). Nursing facilities, staffing, residents and facility deficiencies, 2001 through 2007. Department of Social and Behavioural Sciences, University of California, San Francisco, CA 94118

He, W., Sengupta, M., Velkoff, V., & DeBarros, K. (2005). *65+ in the United States*. Washington, DC: US Census Bureau.

Hoening, H., Landerman, L.R., Shipp, K.M., Pieper, C., Pieper, C., Richardson, M., Pahel, N., & George, L. (2005). A clinical trial of rehabilitation expert clinician versus usual care for providing manual wheelchairs. *Journal of the American Geriatric Society*, 53, 1712-1720.

Ice, G. H. (2002). Daily life in a nursing home: Has it changed in 25 years. *Journal of Aging Studies*, 16, 345-360.

Kane, R.A. (2003). Definition, measurement, and correlates of quality of life in nursing homes: Toward a reasonable practice, research, and policy agenda. *Gerontologist*, 43 (2), 28-36.

Kane, R.A., Caplan, A.L., Urv-Wong, E.K., Freeman, I.C., Aroskar, M.A., & Finch, M. (1997). Everyday matters in the lives of nursing home residents: Wish for the perception of choice and control. *Journal of the American Geriatrics Society*, 45, 1086-1093.

Kasser, V., & Ryan, R. (1999). The relation of psychological needs for autonomy and relatedness to vitality, well-being, and mortality in a nursing home. *Journal of Applied Social Psychology*, 29, 935-954.

Kolanowski, A., Buettner, L., Litaker, M., & Yu, F. (2006). Factors that relate to activity engagement in nursing home residents. *American Journal of Alzheimer's Disease and Other Dementias*, 21, 15-22.

Lenker, J. A., & Paquet, V. L. (2003). A review of conceptual models for assistive technology outcomes research and practice. *Assistive Technology : The Official Journal of RESNA; Assistive Technology : The Official Journal of RESNA*, 15(1), 1-15.

McClain, L., Medrano, D., Marcum, M., & Schukar, J. (2000). A qualitative assessment of wheelchair users' experience with ADA compliance, physical barriers, and secondary health conditions. *Topics in Spinal Cord Injury Rehabilitation*, 6, 99-118.

McGuinn, K. K., & Mosher-Ashley, P. M. (2000). Participation in recreational activities and its effect on perception of life satisfaction in residential settings. *Activities, Adaptation and Aging*, 25, 77-86.

Meyers, A.R., Anderson, J.J., Miller, D.R., Shipp, K., & Hoenig, H. (2002). Barriers, facilitators, and access for wheelchair users: Substantive and methodologic lessons from a pilot study of environmental effects. *Social Sciences and Medicine*, 55, 1435-1446.

Mold, F., Fitzpatrick, J.M., & Roberts, J.D. (2005). Caring for minority ethnic older people in nursing care homes. *British Journal of Nursing*, 14, 601-606.

Morgan-Ellis, J., Alexander, V. D., Cronin, A., Dickinson, M., Fielding, J., Sleney, J., & Thomas, H. (2006). Triangulation and integration: Processes, claims and implications. *Qualitative Research*, 6, 45-59.

Morse, J.M. & Field, P.A. (1995). *Qualitative research methods for health professionals* (2nd ed.) Thousand Oaks, CA: Sage.

Morrow, S.L. (2005). Quality and trustworthiness in qualitative research in counselling psychology. *Journal of Counseling Psychology*, 52, 250-260.

Mortenson, W.B., Miller, W.C., Boily, J., Steele, B., Odell, L. Crawford, E.M. & Desharnais, G. (2005). Perceptions of power mobility use and safety within residential facilities. *Canadian Journal of Occupational Therapy*, 72, 142-152.

Patrick, D. L., Kinne, S., Engelberg, R. A., & Pearlman, R. A. (2000). Functional status and perceived quality of life in adults with and without chronic conditions. *Journal of Clinical Epidemiology*, 53, 779-785.

Perrin, T. (1997). Occupational need in severe dementia: A descriptive study. *Journal of Advanced Nursing*, 25, 934-941.

Post, M.W.M., de Witte, L.P., Schrijvers, A.J.P. (1999) Quality of life and the ICDH: towards an integrated conceptual model for rehabilitation outcomes research. *Clinical Rehabilitation*, 13, 5-15.

Resnick, H.E., Fries, B.E., & Verbrugge, L.M. (1997). Window to their world: The effect of sensory impairments on social engagement and activity time in nursing home residents. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 52, S135-44.

Routhier, F., Vincent, C., Desrosiers, J. & Nadeau, S. (2003). Mobility of wheelchair users: a proposed performance assessment framework. *Disability and rehabilitation*, 25, 19 -34.

Scherer, M.J. (1998). *The Matching Person and Technology (MPT) model and assignment instruments* (3rd ed.). Webster, NY: The institute for Matching Person & Technology.

Schroll, M., Jonsson, P. V., Mor, V., Berg, K., & Sherwood, S. (1997). An international study of social engagement among nursing home residents. *Age and Ageing*, 26 Suppl 2, 55-59.

Shaw, G. & Taylor, S.J. (1991). A survey of wheelchair seating problems of the institutionalized elderly. *Assistive Technology*, 3, 5-10.

Shields M. (2004). Use of wheelchairs and other mobility support devices. *Health Reports*, 15, 37-41.

Tashakkori, A. & C. Teddlie, C. (2003) (Eds.), *Handbook of mixed methods in social and behavioural research*. Thousand Oaks, CA: Sage.

Thomas, W. (1994). *The Eden alternative: Nature, hope and nursing homes*. New York: Eden Alternative Foundation.

Trefler, E., Fitzgerald, S.G., Hobson, D.A., Bursick, T. & Joseph, R. (2004). Outcomes of wheelchair systems intervention with residents of long-term care facilities. *Assistive Technology*, 16, 18-27.

Smithers, J.A. (1990). A wheelchair society: The nursing home scene. *Journal of Aging Studies, 4*, 261-275.

Statistics Canada (2005). *Population projections of visible minority groups, Canada, provinces and regions 2001-2017*. Catalogue no. 91-541-XIE. Ottawa, ON: Demography Division Statistics Canada.

Tashakkori, A. & C. Teddlie, C. (2003) (Eds.), *Handbook of mixed methods in social and behavioural research*. Thousand Oaks, CA: Sage.

Voelkl, J. E., Fries, B. E., & Galecki, A. T. (1995). Predictors of nursing home residents' participation in activity programs. *The Gerontologist, 35*, 44-51.

Voelkl, J.E., Winkelhake, K., Jeffries, J., & Yoshioka, N. (2003). Examination of a nursing home environment: are residents engaged in recreation activities? *Therapeutic Recreation Journal, 37*, 300-314.

Vladeck, B.C. (2003). *Unloving Care* revisited: The persistence of culture. *Journal of Social Work in Long-Term Care, 2*, 1-9.

World Health Organization. (1997). *WHOQOL. Measuring quality of life*. Geneva, Switzerland: World Health Organization.

Zanocchi, M., Maero, B. Nicola, E. Martinelli, E., Luppino, A., Gonella, M., Gariglio, F., Fissore, L. Bardelli, B., & Obialero, R. (2007) Chronic pain in a sample of nursing home residents: Prevalence, characteristics, influence on quality of life (QoL). *Archives of Gerontology and Geriatrics, 47*, 121-128.

Zimmerman, S., Sloane, P.D., Williams, C.S., Reed, P.S., Preisser, J.S., Eckert, J.K., et al. (2005). Dementia care and quality of life in assisted living and nursing homes. *The Gerontologist, 45*, special issue 1, 133-146.

Chapter 4: Predictors of Mobility in Individuals in Residential Care³

In North America, the majority of long-term care facility residents over the age of 65 use wheelchairs as their primary means of mobility (Harrington, Carrillo, & Blank, 2008; Shields, 2004). This represents approximately 800,000 individuals in Canada and the United States (He, Sengupta, Velkoff, & DeBarros, 2005; Statistics Canada, 2007). Approximately half of all residents have a diagnosis of dementia (Harrington, Carrillo, & Blank, 2008; Sahyoun et al., 2001).

Unfortunately, the wheelchairs that many residents receive are commonly inadequate. Problems such as discomfort, immobility, and dysfunctional wheelchairs are experienced by 46% (Simmons, Schnelle, MacRae, & Ouslander, 1995) to 80% of residents (Shaw & Taylor, 1991). Fuchs and Gromak (2003) reported 50% of residents experienced issues such as poor postural alignment and decreased mobility and comfort. Observational studies have found that residents spend only a small proportion of their day propelling their wheelchairs (Brechtelsbauer, & Louie, 1999; Simmons et al.), but this may be related to the equipment provided to them. In two facilities with good access to equipment and prescription services, the majority of residents were independently mobile in their rooms and on their units (Bourbonniere, Fawcett, Miller, Garden, & Mortenson, 2007).

In addition to these equipment related issues, a resident's mobility is affected by a variety of institutional and societal factors. Narrow facility hallways that become crowded with other residents and equipment such as linen carts and lifts may impede wheeled mobility within facilities (Mortenson et al., 2005). These issues may contribute to wheelchair accidents, which, for power wheelchair users, may result in removal of their wheelchairs in accordance with facility protocols (Mortenson et al., 2006). Residents may be immobilized in their wheelchairs by engaging brakes that they cannot release (Smithers, 1990). Limited assistance may be available for residents who are unable to self-propel, which may limit their mobility (Mortenson et al., 2005). Like community-dwelling individuals who use wheelchairs, residents who attempt to use their wheelchairs outside their facilities may encounter accessibility issues and negative reactions from others that discourages or limits their mobility (Cahill &

³ A version of this chapter will be submitted for publication. Mortenson, W.B., Miller, W.C., & Backman, C.L. & Oliffe, J.L., Title: Predictors of Mobility in Individuals in Residential Care

Eggleston, 1995; McClain, Medrano, Marcum, & Schukar, 2000; Meyers et al., 2002; Mortenson et al., 2005).

Some evidence supports the provision of properly prescribed and fitted wheelchairs, but research in this area is limited. A pilot study with 24 residents found that individually prescribed wheelchairs could improve propulsion speed (Trefler, Fitzgerald, Hobson, Bursick & Joseph, 2004). Similarly, in a random sample of residents from two facilities, the only significant predictor of wheeled mobility was the need for intervention to address wheelchair-related problems such as sliding and difficulty propelling (Bourbonniere et al., 2007). However, this study included only a limited number of demographic and wheelchair-related variables and no variables that represented environmental factors.

In light of the proportion of residents who use wheelchairs in these settings and limited research in this area that has indicated mixed benefits associated with use of this assistive technology, a study was undertaken to develop a better understanding of factors that influence the daily mobility of residents who use wheelchairs as their primary means of mobility. To help select and organize variables for inclusion in the study, we framed this project using the Matching Person to Technology model of assistive technology (MPT; Scherer, 1998). This conceptual framework indicates that personal, technological, and environmental factors contribute to outcomes of assistive technology prescription, such as mobility. We undertook this study to identify personal, technological, and environmental factors that predict mobility among residents who use wheelchairs as their primary means of transportation. Based on the MPT model, we hypothesized that variables from each MPT domain would independently contribute to resident's mobility scores.

Methods

To address the study objectives, we conducted a cross-sectional, multi-site research project. The local university ethics board approved the study protocol (see Appendix 2).

Facilities

We created a sampling frame, which included all facilities from a selected portion of the Lower Mainland of British Columbia that had over 100 English speaking, wheelchair-using residents. We invited all 13 facilities in the sampling frame to participate in the study and 11 agreed. Facilities had a mean of 175 beds (SD= 40).

Study Participants

Residents were eligible for inclusion in the study if they 1) used a wheelchair as their primary means of mobility (defined as the means by which they went from their bedrooms to the common rooms), 2) used their wheelchair for more than two hours per day on average, 3) were medically stable, 4) spoke English, 5) were over 60 years of age, 6) had lived in facility for more than one month, and 7) had been using a wheelchair for more than one month.

To act as a surrogate respondent for a resident (described henceforth as a proxy subject), the individual needed to be in at least weekly contact with the resident and speak English well enough to answer the study questions. If the surrogate decision maker met these criteria, he or she was the first individual we invited to act as a proxy. If he or she was unable and no other family member was able to act as a proxy, we approached staff members who were familiar with the residents to act as proxies.

Recruitment

Staff members at each facility identified all residents who were eligible for inclusion in the study and created two lists. One list included all the residents who were able to provide their own consent. The other list included residents who required a surrogate decision maker to provide consent. Resident names were randomized within each list and potential subjects or their surrogate decision makers were invited to participate by a neutral third party at each facility. Recruitment continued either until we enrolled 17 residents from each list from each facility or until all listed persons had been asked.

Measures

As described in detail in Chapter 3, we identified variables for the study based on published empirical research and findings of an exploratory qualitative study that included 16 residents from two residential care facilities. To quantify those variables, we selected measures based on their content, psychometric properties, and utility. When a proxy measure did not exist for a self-report measure, we created one by transforming first person nouns and pronouns to third person ones (i.e., replacing “you” with him/her). We categorized constructs measured in this study into the Person, Technology, and Environmental Domains of the MTP model as illustrated in Figure 4.1.

Higher scores on all the measures indicate increasing amounts of the construct being measured, except for the vision measure. We do not provide published reliability data for independent variables measures, as we calculated study-specific, test-retest intraclass-

correlational coefficients (ICCs) for a subsample of 20 subjects. We only included measures with ICCs >0.8 (described below) in this study. See Appendix 6 for a summary of the measures and copies of the tools.

Dependent Variable

Wheelchair Mobility. We operationalized wheelchair mobility using the Nursing Home Life Space Diameter Measure (NHLSD; Tinetti & Ginter, 1990). The NHLSD is a four item questionnaire that measures the extent and frequency of mobility of long-term care residents during the preceding two weeks within their life spaces, which are defined as the “area[s] throughout which an individual moves during a set period of time” (Tinetti & Ginter, p. 1312). Diameter (extent of mobility) is measured using a four point/level scale, which indicates movement occurs within four concentric zones (1 = bedroom, 2 = unit, 3 = facility, and 4= outside the facility). Frequency is measured using a six point scale (0=never and 5 = > 3 times a day). A mobility score for each zone is calculated by multiplying the diameter by the frequency scores for each zone. These scores are multiplied by two if the resident is able to move in that zone unassisted. A total NHLSD score is calculated by summing the diameter scores, which produces values that range from 0 to 100. Initial psychometric testing of the measure found that the NHLSD was significantly correlated ($r_s=.565$) with social participation and amount of assistance required for ADL function ($r_s=.0.456$). Inter-rater reliability for the measure was ($r = 0.95$) and test-retest reliability ($r = 0.92$) (Tinetti & Ginter, 1990).

Independent Variable Measures

1. Personal Variables. Demographic Information. We collected subject’s age, sex, country of origin, status as a veteran, length of stay in the facility, and diagnoses.

Finances. Daily room rate, which is assessed based on resident’s income after taxes, was used as a surrogate for annual income.

We measured Pain interference using the pain interference question from the SF-12, which measures pain interference on a five category ordinal scale (Jenkinson et al, 1997).

Depression has been associated with decreased life space diameter in community dwelling individuals (Peel et al, 2005; Baker, Bodner, & Allman, 2003). In this study, we measured this construct by using either the 15-item Geriatric Depression Scale (D’Ath, Katona, Mullan, Evans, & Katona, 1994), or the 15-item proxy version (Brown & Schinka, 2005). For question 9, we replaced the word “home” with “nursing home” to ensure clarity.

Cognition. Cognitive ability may affect wheeled mobility, and cognitive declines in power mobility users may result in the removal of their power wheelchairs in these settings (Mendoza, Pittenger, Savage, & Weinstein, 2003; Mortenson et al., 2005). We measured cognition with the Standardized Mini-Mental State Exam (SMMSE; Molloy, 1999).

Functional ability. We measured functional ability using the Functional Independence Measure (FIM; Keith, Granger, Hamilton, & Sherwin, 1987). We omitted item 11, bath transfer, as household bathtubs are normally not present in these facilities and therefore could not be assessed. We excluded item 12 from analysis as it measures mobility performance, which overlaps conceptually with our dependent variable of interest. In addition to a FIM total score, the FIM motor score was created by summing scores for the first eleven included items and the FIM social score was created by summing the last five items of the measure (Keith et al., 1987). Examples of motor items include the ability to transfer and dress; and examples of social items include receptive and productive communication skills.

Health status. We measured health status using the general health question from the SF-12 (Jenkinson et al., 1997), the 18- item Co-Morbidity Index (CMI; Groll, To, Bombardier, & Wright, 2005), and number of regularly scheduled medications.

Vision. We measured vision problems using a one item, five point ordinal scale from the minimum data set (MDS) (2.0) Centers for Medicare & Medicaid Services, 2009).

2. Assistive Technology Variables. Wheelchair type and components. We collected information on the subject's type of wheelchair (power, manual); and wheelchair seating components [(back (sling/personal back), base (sling/hard pan), cushion (none/foam/air/gel/hybrid), footrests (none/elevating/standard), headrests (yes/no)]. We also noted if the resident had more than one wheelchair or owned his or her own wheelchair. For analytic purposes, we dichotomized wheelchairs into power versus manual chairs and facility owned versus resident owned. We collected specific wheelchair seating component information for descriptive purposes only.

Need for seating intervention. Given that appropriate wheelchairs and wheelchair seating have been associated with positive mobility outcomes in this population (Bourbonniere et al. 2007), we measured the need for seating intervention using the Seating Identification Tool (SIT; Miller, Miller, Trenholm, Grant, & Goodman, 2004). Individuals with scores of ≥ 2 require seating intervention (Miller et al.).

Wheelchair skills. We measured wheelchair skills using the Wheelchair Skills Test Questionnaire (WST-Q; Mountain, Kirby, & Smith, 2004) Version 3.2, because it included manual and power mobility formats.

Wheelchair issues. This variable included primarily restraint related wheelchair issues that were not covered in the SIT that we identified during the qualitative phase of the research. We created the variable of wheelchair issues by summing scores for the following five items (yes=1, no=0): 1) inability to release seatbelt, 2) use of a lap tray, 3) sitting on a transfer sling, 4) wheelchair not capable of self-propulsion, and 5) inability to release both brakes.

Additional wheelchair-related variables included length of time using a wheelchair (in months), hours per day spent sitting in a wheelchair, and the presence of a seat belt (yes/no).

Environmental Variables. Environmental barriers. Accessibility barriers have been identified as barriers to mobility among community dwelling wheelchair users (McClain, Medrano, Marcum, & Schukar, 2000; Meyers et al., 2002; Mortenson et al., 2005). We measured environmental barriers using the Craig Hospital Inventory of Environmental Factors (CHIEF) (Whiteneck et al., 2004). We excluded items that covered the work/school domain, as these were not applicable to the residents in our sample. The four remaining domains of the CHIEF included attitudes, services, physical barriers, and policy issues. We replaced the word “home” with “facility” in questions 2, 12, 15, and 18 to prevent ambiguity.

Meaningful Activities. We measured having meaningful things to do in the facility using the Passing the Time domain of the Resident Satisfaction Questionnaire (RSQ), which consists of five 4-choice ordinal items (Chou, Boldy, & Lee, 2002). Example of items from this scale measured resident-specific assessments of the variety and amount of activities offered and opportunities to socialize.

Facility information. To describe the facilities, we collected data on: 1) facility size, 2) funding status (public, not-for-profit or for-profit), 3) direct care staffing ratio (hours of funded care per resident per day), 4) occupational therapy, activity worker/recreational and physiotherapy staffing levels (measured in FTEs), 5) policy of least restraint (yes/no), 6) provision of only basic wheelchairs (yes/no); and 7) power wheelchairs permitted (yes/no).

Additional environmental variables. We collected additional data about other variables that we anticipated would be related to resident mobility including distance (nearest meter) from the resident’s room to the nursing station and the frequency of visits by either friends or family (over the course of week).

Data Collection

Trained raters collected the data for the study. Inter-rater reliability for the WST-Q, FIM, and SIT and test-retest reliability for all measures was determined with a subsample of ten self-responding and ten proxy residents. For retest-reliability, the measures were administered again two weeks later ($M=13.8$ days $SD=2.9$).

Data collection began with the administration of the SMMSE. We administered all subsequent subject-completed measures in a random order to minimize bias due to the order of presentation. We collected data for the SIT, WST-Q, and FIM using a combination of observations by the raters, subject/proxy responses to questions, information from staff and data abstracted from the chart. Raters completed the vision item from the MDS upon completion of data collection. We abstracted diagnostic and demographic information and data required for the CMI from the chart. Total administration time for the measures was approximately two hours.

Analysis

To allow the inclusion of up to 13 variables in each regression model (one variable per ten subjects (Kleinbaum et al, Kupper, Muller, & Nizam, 1998) and based on sample size calculation made using G*Power (Erdfelder, Faul, & Buchner, 1996), a sample size of 132 per subpopulation (proxy and nonproxy) was selected for an overall size of 264. This G*Power sample-size calculation was made based on a Bonferoni corrected Alpha of 0.01, a moderate effect size of 0.55 and a power of 0.80.

We entered data into a desktop statistical program, and data cleaning included verification by spot checking 30% of the records and searching for out of range values prior to the analysis. We used descriptive statistics to characterize the combined, proxy, and self-responding samples. For the WST-Q, if a subject was unable to indicate if a skill was performed, this skill was awarded a score of zero. Wheelchair mobility and other continuous variables, such as age, were expressed as means; and categorical variables were presented as proportions. ANOVA was used to explore differences among facilities, and an unconditional Hierarchical Linear Modeling (HLM) was used to determine if facility variation scores warranted additional analysis.

We created separate regression models for proxy and self-responding subjects, as these populations are different clinically. It was decided, *a priori*, to create a model for the total sample only if cognition was not an independent predictor of mobility scores, as that would

indicate there was no statistical reason that the samples could not be combined. To identify predictors of mobility among self-responding subjects, proxy subjects, and the sample as a whole, we developed three separate parsimonious hierarchical regression models. We entered variables into each hierarchical regression model in blocks, according to the Matching Person to Technology Model. To develop a better understanding of the influence of wheelchair-related factors on mobility, we entered these variables first, followed by personal and environmental factors, into each specific regression model. As there were potentially 26 variables that could be considered for entry into the regression models, to limit the maximum number variables for entry to 13, we determined the variables for inclusion based on plausibility of the relationship, previous published evidence of a relationship between variables, and statistical selection by using bivariable correlations of $r > 0.2$. When there was significant skew or when variables were represented by single items, we dichotomized these variables using previously published or statistically significant cut points ($p \leq 0.05$). When potential collinearity was identified (defined as correlation coefficients among independent variables > 0.7), the measure with the highest correlation with the dependent variable was selected. Before settling on a final model, we considered cases with standardized residuals greater than three standard deviations from the mean for removal (Kleinbaum et al, 1998). We employed list-wise deletion of cases.

Results

We present reliability data for measures included in the study in Appendix 7. Seven of the measures had ICCs above 0.90, and the remainder had ICCs above 0.80. Data were missing for less than 5% of participants for all items except finances. Missing data analyses are presented in Appendix 8.

Of a possible 651 eligible residents at the 11 facilities, 518 were approached (80%) and, of these, 285 consented to take part in the study (55%) of those invited. We included data from 268 residents in the descriptive analysis, as we excluded data for 12 subjects who responded using a combination of self and proxy report. Five of these subjects included self-responding subjects who needed assistance from family to complete the measures, and eight of these were proxy residents who met the cut off score of 15 suggested to be able to complete the GDS independently. Five subjects who did not meet one of the study inclusion criteria. Facilities that participated included one for-profit, two not-for-profit and eight public institutions. We provide detailed descriptions of the facilities in Table 4.1. The study included primarily public facilities, that had a least restraint policy and allowed power wheelchair use. On average 24 (SD=8)

residents participated from each facility with a range from 11 to 35. ANOVA revealed significant differences in NHLSD scores between facilities ($F=2.699$, $p=0.004$). Post hoc testing using Hochberg's GT2 (because of unequal sample sizes (Field, 2000)) indicated that scores from facility 10 were significantly higher than from sites 1, 4, 8, and 11. In the unconditional HLM model the intercept was not significant ($p=0.135$), indicating that the amount of variance between the sites did not warrant further exploration. No significant differences in mobility scores were noted between the eight public facilities and three others (one private and two non-profit) ($T=.991$, $p=.323$). The breakdown of surrogate respondents for proxy subjects was as follows: family members 66.7%, staff members 26.7%, staff and family members together 2.5%, paid companions 3.3%, and friends 0.8%.

The proportion of residents who were independently mobile diminished as distance between their room and each NHLSD zone increased: 63% of all subjects (84% of self-responding subjects and 37% of proxy subjects) were independently mobile on their units, 44% of all subjects (66% of self-responding subjects and 8% of proxy subjects) were independently mobile off their units within their facilities, and 20% of all subjects (34.5% of self-responding subjects and 2.5% of proxy subjects) were independently mobile outside their facilities.

Mean scores or frequencies for the study variables and mean NHLSD total scores for different levels of these variables for the combined, self-responding and proxy subjects are presented in Table 4.2. Across all three groups, most subjects were women from English speaking countries who used a manual wheelchair. Most subjects (59%) were in need of seating intervention based on a cutoff score of 2 (Miller et al., 2004), and most proxy subjects experienced one or more wheelchair issues. For example, 14% had a wheelchair that could not be self-propelled, compared to 1% of self-responding subjects; and 42% had seat belts that could not be self-released, compared to 6% of self-responding subjects. For the total sample, there were significant differences in NHLSD scores for different levels of most independent variables. For the self-responding sample, men, residents who used power wheelchairs, had FIM motor scores ≥ 30 , no wheelchair issues, WST-Q scores ≥ 0.3 , SIT scores < 2 or ≥ 4 visits from friends and family per week had significantly higher NHLSD scores. For the proxy sample, residents who had FIM motor scores ≥ 30 , GDS scores below 5, vision scores < 2 , no wheelchair issues, SIT scores < 2 , WST-Q scores ≥ 0.3 or ≥ 4 visits from friends and family per week.

As noted in Table 4.2, there were significant differences between proxy and self-responding groups on many variables. For example, more subjects in the proxy group were woman or had wheelchair issues. Fewer residents in the proxy group used power wheelchairs or smoked. Proxy subjects had lower incomes, were more depressed, and had used a wheelchair for a shorter amount of time compared to self-responding subjects.

We present correlation matrices between continuous independent variables and NHLSD scores for combined, self-responding and proxy groups in Appendixes 9, 10 and 11. For the combined sample, the variables that were most highly correlated with mobility were wheelchair skills ($r = .66$), and functional independence total score ($r = 0.55$) and cognition ($r = 0.49$). Depression, comorbidity, vision and health status were significantly correlated with mobility only for proxy subjects, while cognition, age, hours per day using the wheelchair and length of wheelchair use were significantly correlated with mobility only for the self-responding subjects.

Because cognition was not an independent predictor of mobility, regression analyses were done for the total sample as well as for the subgroups of self-responding and proxy participants. Six continuous or ordinal variables were dichotomized for entry into the regression models, specifically health, vision, visits, length of wheelchair use, wheelchair issues, and need for seating intervention. No significant cut point for length of wheelchair use was identified, and so this variable was excluded from the regression analyses.

The regression analysis for the total sample is presented in Table 4.3. We used the FIM motor scores and SMMSE scores in this regression model, because the FIM total scores, FIM social cognition scores, and SMMSE scores had intercorrelations > 0.7 . Wheelchair-related variables explained most of the variance in mobility scores. The addition of personal and environmental variables at each additional step resulted in small but significant increases in variance explained. In the final regression model, two assistive technology variables (wheelchair skills and use of power wheelchair), one personal factor (FIM motor scores) and one environmental factor (having four or more visits per week) were significant predictors of mobility. This model accounted for almost half the variance ($r^2 = .48$) in mobility scores among subjects.

Results from the regression analysis for the self-responding sample are presented Table 4.4. In the final model, better wheelchair skills and having a seat belt were significant predictors of increased mobility; and wheelchair skills had the highest standardized beta. The

addition of personal factors did not produce a significant change in the F statistic in the hierarchical model. Having four or more visits per week was a significant environmental factor. This model explained 40% of the variance in mobility scores for self-responding subjects.

The regression analysis for the proxy subjects is presented in Table 4.5. The addition of variables at each step resulted in a significant increase in variance explained. Wheelchair skills were a significant predictor of mobility and had the highest standardized beta. Significant personal factors included FIM total scores and comorbidity. Having four or more visits per week was a significant environmental factor. This model accounted for 37% of the variance in mobility scores for proxy subjects.

Discussion

This is one of the few studies to explore correlates of mobility among individuals in residential care who use wheelchairs as their primary means of mobility. Although the proportion of subjects who were independently mobile in different life spaces was 12-19% higher in this study than among a random sample of residents from two facilities in the same geographical area (Bourbonniere et al., 2007), limited independent mobility was still a common problem. Most self-responding subjects encountered problems with outdoor mobility. Difficulties with outdoor mobility were also identified by participants in the qualitative phase of the study (chapter 2), as doorway thresholds and uneven surfaces made self-propulsion difficult. It is understandable that residents who are not self-responding might be discouraged or prevented from leaving their units or the facility, which may decrease the opportunities for independent mobility in these life spaces; however, a majority of these residents were not independently mobile even within their own units.

Although it was hypothesized that variables from all MPT domains would be significant predictors of mobility for all three groups of subjects, the findings were more mixed. One assistive technology variable and one environmental factor were identified as significant predictors of mobility across the combined and the two subsamples. Wheelchair skills had the highest standardized beta values in all three of the regression models. It seems intuitive that wheelchair skill would enable wheeled mobility performance, and this has been reported among individuals with spinal cord injury (Kilkens, Post, Dallmeijer, van Asbeck, van der Woude, 2005). Family visitors offer various forms of assistance to their relatives in residential care (Gaugler, 2005). Aneshensel, Pearlin, Mullan, Zarit and Whitlatch (1995) found that 50% of family caregivers helped relatives with dementia move about in their facilities, so the

association between mobility and visits from family members appears reasonable. Visitors may encourage or help residents to access life spaces inside and outside the facility with greater frequency, although the converse may also be true: residents who have better independent mobility have more frequent visitors.

Functional ability was the only personal factor that was a significant predictor of mobility among the sample as a whole and for proxy subjects; however, it was not statistically significant among self-responding subjects. The influence of functional ability on mobility for proxy subjects may reflect global declines in ability experienced by proxy subjects who frequently had a diagnosis of dementia. Similarly, functional comorbidity was also a significant predictor of mobility among proxy subjects. We did not identify any personal factors as significant predictors of mobility for self-responding subjects in our regression analysis. However, it should be noted that wheelchair skills, which we labelled as a wheelchair-related variable, likely overlaps with personal and technological factors in the MPT model. In this regard, it seems likely that personal, technological, and environmental factors contribute to independent mobility for all groups as was hypothesized.

There were significant negative correlations between the number of wheelchair issues and mobility scores for all groups; however, this variable did not independently predict mobility. Given the high correlations between wheelchair issues and WST-Q and FIM total scores and the fact that these latter two variables were significant predictors of mobility, it seems that wheelchair issues, which are primarily restraint-related, are more closely associated with functional ability and wheelchair skills than mobility outcomes. The proportion of subjects who were restrained by wheelchairs that could not be propelled or by seat belts that they could not remove is in keeping with findings from other studies. A review of the prevalence of restraint use in residential care facilities found rates, based on nationally representative data in the United States, which ranged from 19.8 to 36% (Castle & Mor, 1998). Although we did not consider the intent with which these devices were used in our study, further reduction in the use of restraints in these facilities could be explored, given the potential for asphyxiation associated with waist restraints (Capezuti, Brush, Won, Wagner, & Lawson, 2008) and the fact that there was no increase in injury to residents following implementation of restraint reduction programs (Tilly & Reed, 2008).

Self-responding residents in need of seating intervention had significantly lower mobility scores; but, unlike previous research (Bourbonniere et al., 2007), the SIT scores were

not significant independent predictors of mobility. This result may reflect the nonrandom nature of the sample in the current study, which on average was more mobile and had greater need for seating intervention than the random sample obtained by Bourbonniere et al. The prevalence of need for seating intervention is in keeping with research by Forward and Miller (2000) that found a prevalence of need for seating intervention of 62.7% from a sample of residents from ten facilities in one Canadian city. This suggests that high rates of wheelchair-related problems, which have previously been identified, remain an issue for residents in these facilities (Fuchs & Gromak, 2003; Simmons et al., 1995; Shaw & Taylor, 1991).

Despite the small numbers of power mobility users (9% of the sample as a whole), use of a power wheelchair was a significant predictor of mobility for the study sample as a whole. Several studies have indicated that power mobility use can facilitate outdoor mobility (Brandt, Iwarsson & Ståhle, 2004; Evans, Frank, Neophytou & de Souza, 2007) and is essential for independent mobility for some facility residents (Mortenson et al., 2005). Power mobility was not a significant predictor of mobility among self-responding residents, but this may reflect a decrease in power associated with the size of the subsample.

Although it might seem odd that having a seat belt was a significant predictor of increased mobility among self-responding subjects, it may be that this device increases mobility confidence among residents; or it may be that residents who are independent with outside mobility are more likely to have a seatbelt to prevent accidental falls from their wheelchairs. In this regard, the seat belt was likely not a restraint, as most self-responding residents experienced no wheelchair issues, which included having a seat belt they were unable to release.

Based on our qualitative research, we had anticipated a greater impact of environmental factors, especially institutional ones. The focus of the CHIEF, however, is on barriers to participation generally, rather than mobility specifically. For this reason, the measure may not have been sensitive enough to capture perceived environmental barriers that affected mobility. This finding may also reflect a well-entrenched personal model of disability in which individuals blame themselves rather than societal practices for difficulties they encounter (Oliver, 1994).

Some predictors of mobility identified in this study may be amenable to intervention. The association between wheelchair skills and mobility suggests that this may be an area for a potential future intervention study. Training residents in wheelchair skills and addressing any

wheelchair-related deficiencies may expand the life spaces that these individuals may enter. A prospective study could also examine the effect of power wheelchair prescription on resident's mobility. Although it may not be possible to increase the number of visits from friends and families, it might be possible for volunteers to provide additional mobility assistance and encouragement.

Some strengths of this study are the large sample size and high reliability of measures used. Although many studies in residential care include either proxy or self-responding subjects, the inclusion of both groups is also a strength. In terms of limitations, we modified some measures from their original format, which may have affected their validity. As subjects we awarded a score of zero if they could not indicate they could perform a given wheelchair skill, this likely created a conservative estimate of their wheelchair skills. As well, most of the measures were based on self or proxy report and may have been affected by a social desirability bias. As a measure of mobility performance, the NHLSD is a relatively crude instrument, as it does not capture distance travelled or time spent moving. Finally, although we attempted to enrol a random sample of residents from the facilities involved in the research, our response rate indicates we ended up with a sample of convenience, which limits the generalizability of the study findings.

There are a number of potential future directions for research suggested by this study. Future studies could supplement self-reported data with the inclusion of more objective measures. Measuring mobility performance by an odometer or global positioning device readings could provide increased granularity for this data. Wheelchair skills could be assessed by skill demonstration. Furthermore, observational measurement of environmental barriers that permit resident-specific data collection might also be beneficial, such as the one currently under development by Cutler, Kane, Degenholtz, Miller, and Grant (2006). The use of structural equation modeling would allow the effect of mediating and moderating variables such as wheelchair issues to be better understood.

Conclusion

Very few studies have explored correlates for mobility among individuals in residential care. This study found that most residents experienced limited independent mobility in different life spaces. Regression analyses revealed that wheelchair skills were the most important predictors of mobility and visits from family and friends was an important environmental

factor. This study lays the groundwork for additional research in this area, which might include an intervention study which attempts to improve wheelchair skills among residents.

Table 4.1: Descriptive Facility Data

Site number ^a	Direct care staffing ratio	OT	RT	AW	PT	Ownership	Eden	Least Restraint	Purchase	Scooter	Power
1	1.95	1.30	0.52	2.08	Pub	Y	Y	N	N	Y	
2	2.8	1.34	0.67	2.68	Pub	Y	Y	N	Y	Y	
3	2.84	0.68	0.54	2.04	Pub	Y	Y	Y	Y	Y	
4	2.8	0.31	0.05	0.31	Pub	N	Y	Y	N	Y	
5	2.4	0.67	1.00	5.07	Priv	N	Y	Y	N	Y	
6	2.8	0.70	0.56	2.10	Pub	Y	Y	Y	N	Y	
7	2.4	0.67	1.00	5.07	Pub	Y	Y	N	N	Y	
8	2.3	0.26	0.18	0.66	Pub	N	Y	Y	N	N	
9	1.9	0.00	0.14	1.27	NFP	Y	Y	Y	Y	Y	
10	2.8	0.85	0.85	1.71	NFP	N	Y	Y	N	Y	
11	3.6	0.68	0.54	2.36	Pub	Y	Y	Y	Y	Y	
M (SD) / (N) %	2.6(0.48)	0.68 (0.40)	2.3(1.54)	0.55 (0.33)	8 Pub (73%)	7(64%)	(11) 100%	(7) 64%	(4) 36%	(10) 91%	

a= number of beds has been omitted to protect the identity of facilities, Eden = facility has adopted the Eden alternative, Least Restraint= least restraint policy in place, M= mean, NFP=not for profit facility, N= number, OT= Occupational therapist full time equivalents (FTE)s per 100 residents, PT= Physiotherapist FTEs per 100 residents, Power= facility allows use of power wheelchairs, Priv=private for profit facility, Pub= public facility, Purchase= facility encourages residents to purchase own wheelchair, Scooter= facility allows use of scoters, SD=standard deviation

Table 4.2: Descriptive Statistics and Mean Nursing Home Life Space Diameter Score (NHLSD) for Combined, Self-responding and Proxy Subject Groups

Name	Combined		Self-responding		Proxy	
	%	Mean NHLSD	%	Mean NHLSD	%	Mean NHLSD
Personal Factors						
Age ^a (yrs.) M (SD)	84.15 (8.62)		82.64 (8.78)		86.03 (8.06)	
≥84	58.65	38.49 ^b	49.32	46.21	70.34	31.71
<84	41.35	44.87 ^b	50.68	51.93	29.66	29.74
Comorbidity	3.08 (1.94)		3.24 (1.97)		2.88 (1.89)	
≥3	57.36	41.63	59.18	48.06	55.08	33.03
<3	42.64	40.35	40.82	50.55	44.92	28.79
Daily Rate ^a (\$)	42.65 (16.16)		39.85 (14.84)		46.12 (17.10)	
≥43	38.11	38.63	29.63	48.78	48.62	30.98
<43	61.89	42.74	70.37	49.41	51.38	31.43
English COB						
Y	83.20	40.87	83.90	48.65	82.40	30.93
N	16.80	42.40	16.10	51.46	17.60	32.05
FIM Motor ^a	34.73 (17.86)		44.03 (16.12)		23.05 (12.21)	
≥30	41.73	51.62 ^b	64.19	52.43 ^b	13.56	46.81 ^b
<30	58.27	33.62 ^b	35.81	43.15 ^b	86.44	28.67 ^b
FIM Total ^a	59.03 (25.54)		75.49 (17.44)		38.39 (17.97)	
≥55	50.38	51.25 ^b	81.76	51.45 ^b	11.02	49.38 ^b
<55	49.62	30.86 ^b	18.24	38.63 ^b	88.98	28.87 ^b
GDS ^a	5.11 (3.52)		3.99 (3.00)		6.50 (3.64)	
≥5	52.30	36.53 ^b	39.50	46.31	68.40	29.44 ^b
<5	47.70	46.38 ^b	60.50	51.03	31.60	35.19 ^b
Health ^a	1.91 (1.08)		2.11 (1.10)		1.67 (1.00)	
≥3	29.32	46.51 ^b	36.49	50.87	20.34	36.71 ^b
<3	70.68	38.90 ^b	63.51	48.10	79.66	29.70 ^b
Length of Stay	32.82 (37.09)		33.34 (42.49)		32.16 (29.09)	
≥33months	32.08	40.84	28.38	51.90	36.75	30.02
<33months	67.92	41.40	71.62	48.00	63.25	31.95
Meds ^a	7.96 (3.36)		8.49 (3.33)		7.28 (3.28)	
≥8	52.29	42.09	62.59	47.63	39.13	30.78
<8	47.71	40.50	37.41	51.75	60.87	31.67
Sex ^a						
Female	69.00	38.66 ^b	63.80	45.66 ^b	75.60	31.27
Male	31.00	46.58 ^b	36.20	55.11 ^b	24.40	30.69

Name	Combined		Self-responding		Proxy	
	%	Mean NHLSD	%	Name	%	Mean NHLSD
SMMSE ^a	15.44 (10.69)		23.91 (4.11)		4.67 (5.52)	
≥15	55.85	48.85 ^b	97.97	49.30	2.56	27.33
<15	44.15	31.21 ^b	2.03	40.00	97.44	30.97
Smoker ^a						
Y	4.50	57.58 ^b	7.40	59.64	0.80	35.00
N	95.50	40.35 ^b	92.60	48.26	99.20	31.09
Vision	0.77 (1.09)		0.65 (1.05)		0.91 (1.12)	
≥2	20.00	35.30 ^b	16.90	46.08	23.90	25.68 ^b
<2	80.00	42.63 ^b	83.10	49.72	76.10	32.83 ^b
Wheelchair Related Factors						
Hours in WC	8.89 (3.65)		8.83 (3.87)		8.96 (3.36)	
≥9	54.55	43.13	54.05	51.70	55.17	32.42
<9	45.45	39.13	45.95	46.06	44.83	30.06
Length of WC use (months) ^a	45.05 (69.47)		54.50 (88.38)		33.12 (28.99)	
≥13	69.20	42.36	68.3	55.18	70.43	31.57
<13	30.80	38.84	31.7	44.61	29.56	31.03
Owns WC ^a						
Y	33.00	45.16 ^b	39.60	51.95	24.60	31.34
N	67.00	39.14 ^b	60.40	47.22	75.40	31.06
Power Chair ^a						
Y	9.00	61.83 ^b	15.50	62.96 ^b	0.80	36.00
N	91.00	39.08 ^b	84.50	46.56 ^b	99.20	31.09
SIT	2.14 (1.77)		2.10 (1.80)		2.19 (1.73)	
≥2	59.00	39.34	57.40	46.33 ^b	61.00	31.08
<2	41.00	43.72	42.60	52.86 ^b	39.00	31.20
WC issues ^a	0.87 (1.15)		0.34 (0.72)		1.49 (1.25)	
≥1	45.50	30.95 ^b	23.60	38.94 ^b	72.00	27.94 ^b
<1	55.50	48.18 ^b	76.40	50.91 ^b	28.00	39.33 ^b
WST-Q ^a	0.31 (0.22)		0.42 (0.18)		0.16 (0.17)	
≥0.3	52.60	51.88 ^b	78.50	54.43 ^b	20.20	40.44 ^b
<0.3	47.40	28.38 ^b	21.50	27.67 ^b	79.80	28.62 ^b
Environmental Factor						
RSQ passing time	8.14 (3.00)		8.10 (2.95)		8.20 (3.08)	
≥8	58.11	42.75	57.82	52.06	58.47	31.29
<8	41.89	38.89	42.18	45.21	41.53	30.90
Visits per week	3.37 (3.29)		2.83 (2.94)		4.06 (3.58)	

a	Combined		Self-responding		Proxy	
	≥4	36.60	44.62 ^b	30.20	56.40 ^b	44.50
<4	63.40	39.13 ^b	69.80	45.92 ^b	55.50	28.53 ^b

a=significant difference between self-responding and proxy subjects, b=significant difference in NHLSD mean scores based on cut point, COB Country of Birth FIM = Functional Independence Measure, GDS = Geriatric Depression Scale, RSQ= Resident Satisfaction Questionnaire, SIT= Seating Identification Tool, SMMSE=Standardized Mini Mental Status Exam WC= Wheelchair WST-Q= Wheelchair Skills Test Questionnaire

Table 4.3: NHLSD Regression Analysis for Total Sample (N=257)

Steps	Assistive Technology Factors					Personal Factors					Environmental Factors				
	β	<i>SE</i>	S β	LB	UB	β	<i>SE</i>	S β	LB	UB	β	<i>SE</i>	S β	LB	UB
(Constant)	23.86	2.65		18.65	29.08	34.52	1.28		14.28	54.75	26.49	1.29		6.23	46.75
WST-Q	54.47	5.80	.62	43.06	65.89	37.50	7.70	.43	22.34	52.66	37.54	7.52	.43	22.73	52.35
Power Chair	6.80	3.50	.10	-.08	13.68	9.12	3.78	.14	1.69	16.56	8.96	3.69	.13	1.70	16.23
WC Issues	-.34	2.33	-.01	-4.92	4.24	.36	2.35	.01	-4.27	4.99	-.01	2.30	.00	-4.53	4.52
Owens WC	.03	1.98	.00	-3.86	3.92	.52	2.01	.01	-3.44	4.48	.81	1.96	.02	-3.06	4.68
GDS						-.33	.29	-.06	-.91	.25	-.24	.29	-.04	-.81	.33
FIM Motor						.22	.09	.18	.05	.38	.20	.08	.17	.04	.36
sex						1.70	2.05	.04	-2.33	5.73	1.15	2.00	.03	-2.80	5.10
smoking						2.87	4.48	.03	-5.94	11.69	5.46	4.43	.06	-3.26	14.19
age						-.15	.11	-.07	-.37	.07	-.09	.11	-.04	-.31	.13
Vision \geq 2						-.68	2.30	-.01	-5.20	3.84	-.61	2.24	-.01	-5.03	3.81
SMMSE						2.36	2.15	.06	-1.87	6.60	2.78	2.10	.07	-1.37	6.92
Health \geq 3						.02	.12	.01	-.21	.25	.07	.12	.04	-.16	.29
Visits \geq 4											6.66	1.86	.17	3.00	1.31
Cum. Adj. r^2		.44						.46					.48		
Adj. r^2		--						.02					.02		
change per step															

Abbreviations: *SE* = Standard Error, S β = Standardized β , Sig. = Significance, LB = lower 95% confidence interval for β , UB = upper 95% confidence interval for β , FIM = Functional Independence Measure, GDS = Geriatric Depression Scale, SIT= Seating Identification Tool, SMMSE=Standardized Mini Mental Status Exam, WC= Wheelchair, WST-Q= Wheelchair Skills Test Questionnaire, **bold**= significant $p \leq 0.05$

Table 4.4: NHLSD Regression Analysis for Self-responding Sample (N=139)

Steps	Assistive Technology Factors					Personal Factors					Environmental Factors				
	β	<i>SE</i>	S β	LB	UB	β	<i>SE</i>	S β	LB	UB	β	<i>SE</i>	S β	LB	UB
(Constant)	22.57	5.53		11.63	33.51	25.92	18.78		-11.24	63.08	24.69	18.49		-11.89	61.26
WST-Q	51.68	9.21	.48	33.47	69.90	39.15	10.73	.37	17.91	6.38	38.07	1.57	.36	17.16	58.99
Seatbelt	9.00	3.26	.21	2.55	15.45	8.76	3.24	.20	2.34	15.18	9.69	3.22	.22	3.33	16.06
hours in WC	.34	.35	.07	-0.35	1.04	0.40	0.36	.08	-.31	1.11	.38	.35	.07	-.32	1.07
power chair	4.47	4.25	.08	-3.93	12.87	5.69	4.62	.11	-3.44	14.82	6.14	4.55	.11	-2.85	15.14
SIT	-1.61	2.77	-.04	-7.08	3.86	-0.07	2.85	.00	-5.71	5.58	-.05	2.81	.00	-5.60	5.50
WC Issues	-6.28	3.82	-.14	-13.84	1.29	-5.56	3.83	-.12	-13.14	2.02	-6.30	3.78	-.14	-13.78	1.19
FIM Total						0.17	0.10	.14	-.04	.37	.16	.10	.13	-.04	.37
SMMSE						0.23	0.36	.05	-.48	.94	.07	.36	.02	-.64	.79
sex						2.85	2.90	.07	-2.89	8.58	3.28	2.86	.08	-2.37	8.93
age						-0.22	0.16	-.10	-.53	.10	-.17	.16	-.08	-.49	.14
Visits \geq 4											6.93	3.01	.16	.98	12.88
Cumulative. Adj. r^2		.37											.38		.40
Adj. r^2 change per step		.37											.01		.02

Abbreviations: *SE* = Standard Error, S β = Standardized β , Sig. = Significance, LB = lower 95% confidence interval for β , UB = upper 95% confidence interval for β , FIM = Functional Independence Measure, GDS = Geriatric Depression Scale, SIT= Seating Identification Tool, SMMSE=Standardized Mini Mental Status Exam, WC= Wheelchair, WST-Q= Wheelchair Skills Test Questionnaire, **bold**= significant $p \leq 0.05$

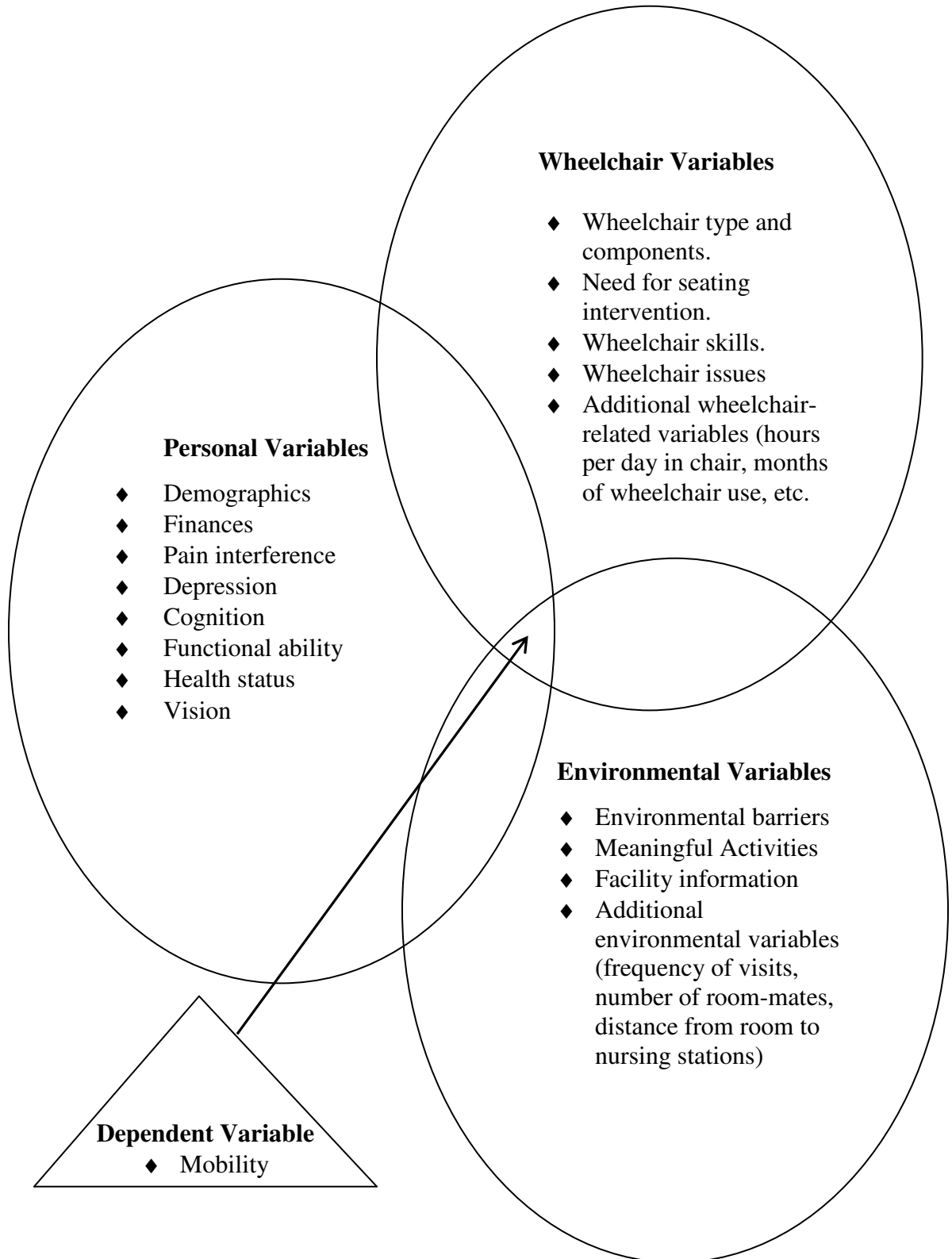
Table 4.5: NHLSD Regression Analysis for Proxy Subjects (N=116)

Steps	Assistive Technology Factors					Personal Factors					Environmental Factors				
	β	<i>SE</i>	$S\beta$	LB	UB	β	<i>SE</i>	$S\beta$	LB	UB	β	<i>SE</i>	$S\beta$	LB	UB
(Constant)	29.30	3.28		22.81	35.79	2.89	5.40		1.19	31.59	18.89	5.33		8.33	29.45
WST-Q	3.45	8.10	.40	14.41	46.49	15.92	8.94	.21	-1.80	33.63	19.30	8.83	.26	1.81	36.80
WC Issues	-4.02	2.97	-.15	-9.90	1.86	-.58	3.09	-.02	-6.71	5.56	-.52	3.02	-.02	-6.50	5.47
GDS Total						-.40	.29	-.12	-.98	.18	-.29	.29	-.08	-.86	.29
Health > 3						3.15	2.51	.10	-1.81	8.12	3.21	2.45	.10	-1.64	8.06
FIM Total						.22	.09	.29	.04	.41	.19	.09	.24	.00	.37
Comorbidity						1.04	.53	.16	-.01	2.09	1.02	.52	.15	.00	2.04
Vision > 2						-2.77	2.34	-.10	-7.42	1.87	-3.05	2.29	-.10	-7.58	1.49
Visits > 4											4.86	1.92	.19	1.05	8.67
Cumulative Adj. r^2		.26						.34					.37		
Adj. r^2 change per step		.26						.08					.03		

Abbreviations: *SE* = Standard Error, $S\beta$ = Standardized β , Sig. = Significance LB = lower 95% confidence interval for β , UB = upper 95% confidence interval for β , FIM = Functional Independence Measure, GDS = Geriatric Depression Scale, SIT= Seating Identification Tool, SMMSE=Standardized Mini Mental Status Exam, WC= Wheelchair, WST-Q= Wheelchair Skills Test Questionnaire, **bold**= significant $p \leq 0.05$

Figure 4.1

Constructs Included in the Study Organized According to the Matching Person to Technology Model



References

- Aneshensel, C.S., Pearlin, L.I., Mullan, J.T., Zarit, S.H., & Whitlatch, C.J. (1995). *Profiles in caregiving: The unexpected career*. Academic Press; San Diego, CA.
- Baker, P.S., Bodner, E.V., & Allman, R.M. (2003). Measuring life-space mobility in community-dwelling older adults. *Journal of the American Geriatrics Society, 51*, 1610-1614.
- Bourbonniere, M.C., Fawcett, L.M., Miller, W.C., Garden, J., & Mortenson, W.B. (2007). Prevalence and predictors of need for seating intervention and mobility for persons in long-term care. *Canadian Journal on Aging, 26*, 195, 204.
- Brechtelsbauer, D. & Louie, A. (1999). Wheelchair use among long-term care residents. *Annals of Long Term Care, 7*, 213-20.
- Brandt, Å, Iwarsson, S., & Ståhle, A. (2004). Older people's use of powered wheelchairs for activity and participation. *Journal of Rehabilitation Medicine, 36*, 70-77.
- Brown, L.M., Schinka, J.A. (2005). Developmental and initial validation of a 15-item informant version of the geriatric depression scale. *International Journal of Geriatric Psychiatry, 20*, 911-918.
- Cahill, S.E. & Eggleston, R. (1995). Reconsidering the stigma of physical disability: Wheelchair use and public kindness. *Sociological Quarterly, 36*, 681-698.
- Capezuti, E., Brush, B.L., Won, R.M., Wagner, L.M., & Lawson, W.T. (2008). Least restrictive or least understood? Waist restraints, provider practices, and risk of harm. *Journal of Aging & Social Policy, 20*, 305-322.
- Castle, N.G., & Mor, V. (1998). Physical restraints in nursing homes: A review of the literature since the nursing home reform act of 1987. *Medical Care Research and Review, 55*, 139-170.
- Centers for Medicare & Medicaid Services (2009). MDS 2.0 Manual and Forms. Downloaded March 10, 2009 from http://www.cms.hhs.gov/MinimumDataSets20/025_ManualsAndForms.asp#TopOfPage.
- Chou, S.C., Boldy, D.P., & Lee, A.H. (2002). Resident satisfaction and its components in residential aged care. *The Gerontologist, 42*, 188-198.
- D'ath, P., Katona, P., Mullan, E., Evans, S., & Katona, C. (1994). Screening, detection and management of depression in elderly primary care attenders. I: The acceptability and performance of the 15 item geriatric depression scale (GDS15) and the development of short versions. *Family Practice, 11*, 260-266.

Erdfelder, E., Faul, F., & Buchner, A. (1996). GPOWER: A general power analysis program. *Behaviour Research Methods, Instruments, & Computers*, 28, 1-11.

Evans, S., Frank, A.O., Neophytou, C., & de Souza, L. (2007). Older adults' use of, and satisfaction with, electric powered indoor/outdoor wheelchairs. *Age and Ageing*, 36, 431-435.

Field, A. P. (2000). *Discovering statistics using SPSS for Windows: Advanced techniques for the beginner*. London: Sage.

Forward, J. A. & Miller, W.C. (2000). The prevalence of wheelchair and seating intervention needs in long-term care in London, Ontario. Unpublished research project, University of Western Ontario, London, Canada.

Fuchs, R.H. & Gromak, P.A. (2003). Wheelchair use by residents of nursing homes: Effectiveness in meeting positioning and mobility needs. *Assistive Technology*, 15, 151-163.

Gaugler, J.E. (2005). Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health*, 9, 105-118.

Groll, D.L., To, T., Bombardier, C., & Wright, J.G. (2005). The development of a comorbidity index with physical function as the outcome. *Journal of Clinical Epidemiology*, 58, 595-602.

He, W., Sengupta, M., Velkoff, V., & DeBarros, K. (2005). *65+ in the United States*. Washington, DC: US Census Bureau.

Herrington, C., Carrillo, H., & Blank, B.W. (2008). Nursing facilities, staffing, residents and facility deficiencies, 2001 through 2007. Department of Social and Behavioural Sciences, University of California, San Francisco, CA 94118

Jenkinson, C., Layte, R., Jenkinson, D., Lawrence, K., Petersen, S., Paice, C., & Stradling, J. (1997). A shorter form health survey: can the SF-12 replicate results from the SF-36 in longitudinal studies? *Journal of Public Health Medicine*, 19, 179-186.

Keith R.A., Granger, C.V., Hamilton, B.B., & Sherwin, F.S. (1987). The functional independence measure: A new tool for rehabilitation. *Advances in Clinical Rehabilitation*, 1, 6-18.

Kilkens, O.J., Post, M.W., Dallmeijer, A.J., van Asbeck, F.W., van der Woude, L.H. (2005). Relationship between manual wheelchair skill performance and participation of persons with spinal cord injuries 1 year after discharge from inpatient rehabilitation. *Journal of Rehabilitation and Research Development*, 42, 65-73.

Kleinbaum, D.G., Kupper, L.L., Muller, K.E., & Nizam, A. (1998). *Applied regression analysis and other multivariable methods*. Pacific Grove, CA: Cole Publishing Company.

McClain, L., Medrano, D., Marcum, M., & Schukar, J. (2000). A qualitative assessment of wheelchair users' experience with ADA compliance, physical barriers, and secondary health conditions. *Topics in Spinal Cord Injury Rehabilitation, 6*, 99-118.

Mendoza, R.J., Pittenger, D.J., Savage, F.S. A protocol for assessment of risk in wheelchair driving within a healthcare facility. *Disability & Rehabilitation, 25*, 520-526.

Miller, W.C., Miller, F., Trenholm, K., Grant, D., & Goodman, K. (2004). Development and preliminary assessment of the measurement properties of the Seating Identification Tool (SIT). *Clinical Rehabilitation, 18*, 317-25.

Molloy, D. W. (1999). *The Standardized Mini-Mental Status Exam (SMMSE)*. New Grange Press, Troy, Ontario, Canada.

Mortenson, W.B., Miller, W.C., Boily, J., Steele, B., & Crawford, E.M. & Desharnais, G. (2006). Overarching principles and salient findings for inclusion in guidelines for power mobility use within residential care facilities *Journal of Rehabilitation Research and Development, 43*, 199-208.

Mortenson, W.B., Miller, W.C., Boily, J., Steele, B., Odell, L. Crawford, E.M. & Desharnais, G. (2005). Perceptions of power mobility use and safety within residential facilities. *Canadian Journal of Occupational Therapy, 72*, 142-152.

Mountain, A.D., Kirby, R.L., & Smith, C. (2004). The wheelchair skills test, version 2.4: Validity of an algorithm-based questionnaire version. *Archives of Physical Medicine and Rehabilitation, 85*, 416-423.

Meyers, A.R., Anderson, J.J., Miller, D.R., Shipp, K., & Hoenig, H. (2002). Barriers, facilitators, and access for wheelchair users: Substantive and methodologic lessons from a pilot study of environmental effects. *Social Sciences and Medicine, 55*, 1435-1446.

Oliver, M. (1990). *The politics of disablement: A sociological approach*. London: St. Martin's Press.

Peel, C., Baker, P.S., Roth, D.L., Brown, C.J., Bodner, E.V., & Allman, R.M. (2005). Assessing mobility in older adults: The UAB study of aging life-space assessment. *Physical Therapy, 85*, 1008-1019.

Sahyoun, N.R., Pratt, L.A., Lentzner, H., Dey, A., & Robinson, K.N. (2001). The changing profile of nursing home residents: 1985-1997. *Aging Trends, 1-8*.

Scherer, M.J. (1998). *The Matching Person and Technology (MPT) model and assessment instruments* (3rd ed.) Webster, NY: The Institute for Matching Person & Technology.

Shaw, G. & Taylor, S.J. (1991). A survey of wheelchair seating problems of the institutionalized elderly. *Assistive Technology*, 3, 5-10.

Shields M. (2004). Use of wheelchairs and other mobility support devices. *Health Reports*, 15, 37-41.

Simmons, S. F., Schnelle, J. F., MacRae, P. G., & Ouslander, J. G. (1995). Wheelchairs as mobility restraints: Predictors of wheelchair activity in nonambulatory nursing home residents. *Journal of the American Geriatrics Society*, 43, 384-388.

Smithers, J.A. (1990). A wheelchair society: The nursing home scene. *Journal of Aging Studies*, 4, 261-275.

Teresi, J., Abrams, R., Holmes, D., Ramirez, M., & Elmicke, J. (2001). Prevalence of depression and depression recognition in nursing homes. *Social Psychiatry and Psychiatric Epidemiology*, 36, 613-620.

Tilly, J., & Reed, P. (2008). Falls, wandering, and physical restraints: A review of interventions for individuals with dementia in assisted living and nursing homes. *Alzheimer's Care Today*, 9, 45-50.

Tinetti, M.E. & Ginter, S.F. (1990). The nursing home life-space diameter. A measure of extent and frequency of mobility among nursing home residents. *Journal of the American Geriatrics Society*, 38, 1311-1315.

Trefler, E., Fitzgerald, S.G., Hobson, D.A., Bursick, T. & Joseph, R. (2004). Outcomes of wheelchair systems intervention with residents of long-term care facilities. *Assistive Technology*, 16, 18-27

Whiteneck, G.G., Harrison-Felix, C.L., Mellick, D.C., Brooks, C.A., Charlifue, S.B., & Gerhart, K.A. (2004). Quantifying environmental factors: A measure of physical, attitudinal, service, productivity, and policy barriers. *Archives of Physical Medicine and Rehabilitation*, 85, 1324-1335.

Chapter 5: Predictors of Participation and Life Satisfaction among Long-term Care Residents Who Use Wheelchairs As a Primary Means of Mobility⁴

Serious concerns have been raised about quality of life and activity engagement among those living in long-term care. Ethnographic studies have documented denigrating aspects of residential care facilities (Fiveash, 1998; Kayser-Jones, 1981; Vladeck, 2003), and observational studies have indicated residents with dementia experience decreased well-being, which may be due, in part, to institutional environments that fail to accommodate these individuals (Chung, 2004; Perrin, 1997). Over the past 30 years, observational studies have found that residents spend most of their time doing nothing or in passive activities such as sleeping or waiting (Gottesman & Bourestom, 1974; Ice, 2002; Shore, Lerman, Smith, Iwata, & DeLeon, 1995). Boredom is a common concern among residents (Slama & Bergman-Evans, 2000; Thomas, 1994), which was also identified as an issue in our preliminary qualitative study [see chapter 2].

Although institutional factors have an important influence, many residents have physical and cognitive impairments, which may also affect their participation in activity and satisfaction with life. Residents are generally admitted to residential care facilities because of multiple functional issues that prevent them from caring for themselves (McGregor, Tate, Ronald & McGrail, 2007) and that may limit their engagement in social activities (Kolanowski et al., 2006; Schroll et al., 1997).

Problems with functional ambulation mean that most individuals in residential care in North America use wheelchairs as their primary means of mobility (Herrington, Carrillo and Blank, 2008; Shields, 2004). Power and manual wheelchair use has been associated with improved participation and quality of life in some populations (Barker, Reid & Cott, 2006; Brandt, et al, 2004; Devitt, Chaur, Jutai, 2003; Petterson, Törnquest, & Ahlström, 2006). Given that residents often receive wheelchairs that are uncomfortable and difficult to propel (Fuchs & Gromak, 2003; Forward, 2000), their participation and quality of life may be adversely affected. No research, however, has examined this relationship.

To facilitate positive outcomes of assistive technology prescription, the Matching Person to Technology (MPT) model posits that personal, environmental and assistive technology factors

⁴ A version of this chapter will be submitted for publication. Mortenson, W.B., Miller, W.C., & Backman, C.L. & Oliffe, J.L., Title: Predictors of participation and life satisfaction among long-term care residents who use wheelchairs as a primary means of mobility.

need to be carefully considered (Scherer, 1998). Unfortunately, research that has attempted to identify predictors of resident's participation and quality of life has focused almost exclusively on personal factors, without documenting the use of assistive technology. These studies have found that activity engagement was negatively associated with visual and auditory impairments (Resnick, Fries, & Verbrugge, 1997), pain (Cadogan et al. 2008) and depression (Voelkl et al., 1995) and that residents with cognitive impairments such as advanced dementia had lower levels of engagement in social and other activities (Chung, 2004; Kolanowski, Buettner, Litaker, & Yu, 2006; Perrin, 1997; Schroll, Jonsson, Mor, Berg & Sherwood, 1997; Voelkl, Fries, Galecki, 1995). Without documenting assistive technology use in the preceding studies, wheelchair-related factors represent unacknowledged, potentially confounding variables (Rust & Smith, 2005).

Research on predictors of quality of life among residents has also focused primarily on personal factors, described below, without measuring wheelchair-related factors. Personal variables that have been associated with subjective well-being include cognition (Chung, 2004; Edelman, Fulton, Kuhn, & Chang, 2005), functional status (Edelman, Fulton, Kuhn, & Chang, 2005; Patrick, Kinne, Engelberg, & Pearlman, 2000), health (Patrick et al., 2000), realizing expectations (Ghusn, Hyde, Stevens, Hyde, & Teasdale, 1996), and depression (Patrick et al., 2000). McGuinn and Mosher-Ashley (2000) found that life satisfaction was associated with engagement in self-generated activities rather than facility organized ones. In terms of environmental factors, social support has been associated with quality of life among residents (Kasser & Ryan, 1999). Kane et al. (2004) found that residents from rural and not-for-profit settings had higher scores on some of their quality of life scales. Institutional changes, like the adoption of the Eden alternative, a resident-empowering model of care, have been associated with improvements in quality of life in some settings (Bergman-Evans, 2004). Better staff training, staff attitude and resident-staff communication have been related to higher quality of life among residents with dementia (Zimmerman et al., 2005). The preceding research emphasises the influence of personal and institutional factors on resident's quality of life.

Research that has focused exclusively on residents who use wheelchairs suggests a relationship between wheelchair use and participation and quality of life outcomes that place special emphasis on environmental and wheelchair-related factors. A pilot study found that individually prescribed wheelchairs improved resident's health-related social function (Trefler, Fitzgerald, Hobson, Bursick & Joseph, 2004). Although power wheelchairs are intended to increase mobility, a qualitative study found that residents who used these devices in the

community reported discrimination and accessibility issues that negatively affected their participation and quality of life (Mortenson et al., 2005). Ethnographic studies have found wheelchairs are sometimes used as a method of restraining residents, by applying brakes that residents cannot release or seat belts they cannot remove (Gubrium, 1975; Smithers, 1990), which might limit their ability to participate in activities and alter their sense of well-being (Castle & Mor, 1998). In this regard, it seems that wheelchair-related factors may also influence resident's participation and quality of life.

Given the prevalence of wheelchairs in these settings, potential issues around their use, and lack of research exploring their influence on participation and quality of life outcomes, a study was undertaken to explore the relationship between wheelchair-related factors, and resident's participation and quality of life, with the intent of identifying areas suitable for future intervention. Our research questions were as follows:

1. What is the relationship between wheelchair-related factors and participation among residents living in long-term care facilities who use wheelchairs as their primary means of mobility?
2. What is the relationship between wheelchair-related factors and quality of life among these residents?

As Post, de Witt, and Schrijvers (1999) proposed that there was a hierarchical relationship between impairment, function, disability, and quality of life. Based on this model and the modified Matching Person to Technology model we developed in Chapter 3 (Figure 3.1), we hypothesized that wheelchair-related factors would be more strongly associated with participation than quality of life outcomes, as wheelchair-related factors would have a more direct influence on mobility and participation than quality of life.

Methods

We used a cross-sectional design, employing the administration of a variety of standardized and study-specific measures to residents who could self-respond or those who required the use of surrogate respondents. The local university ethics board as noted in Appendix 2 approved the study.

Settings

A sampling frame was created, which included facilities that reported having at least 100 residents who used wheelchairs, were in a selected geographical portion of Lower Mainland of British Columbia, and were not intended exclusively for residents who spoke English. All

facilities in the sampling frame were invited to participate in the research. Thirteen facilities were contacted, and 11 agreed to participate. Facilities had an average of 175 beds (SD=40).

Study Participants

To participate residents needed to 1) use wheelchairs to get from their beds to the common rooms on the unit, with or without the assistance of others, 2) use their wheelchairs for more than two hours per day on average, 3) be medically stable, 4) speak English and 5) be over 60 years of age. We excluded residents if they were 1) acutely ill, 2) were bed-bound, 3) had been in the facility for less than one month, or 4) had been using wheelchairs for less than one month. We also excluded residents if they were not able to provide their own consent and did not have a surrogate decision maker who could provide consent.

To act as a proxy for a resident who was not able to provide their own consent (described henceforth as a proxy subject), the individual had to be in at least weekly contact with the subject and to speak English well enough to answer the study questions. If the surrogate decision maker met these criteria, that person was the first individual who was invited act as a proxy. If neither that person nor another family member was able to act as a proxy, we approached staff members who worked with the residents on a regular basis.

Recruitment

Staff members at each facility created two lists of eligible residents. One list included all residents who met the inclusion criteria and who were deemed able to respond reliably to examples of study questions provided and to understand the risks involved in participation well enough to provide their own consent. The other list included residents who required a surrogate decision maker to provide consent. We drew a simple, random selection of residents from these lists; and a third party at each facility invited selected individuals to participate directly or by a surrogate decision maker, until either 17 residents from each list from each facility had been enrolled in the study or until all listed persons had been asked.

Measurement

Independent Variables

We selected measures for the study based on 1) the findings from the preliminary qualitative phase of this research project, 2) their sound psychometric properties and 3) literature supporting measurement of the variable in this area study. We organized these variables according to the person, assistive technology, and environmental domains of the Matching Person to Technology Model of assistive technology (Scherer, 1998) to help distinguish wheelchair-related factors from other elements of the environment. When a proxy measure did

not exist for a self-report measure, we created one by transforming second and second person nouns and pronouns to third person ones, e.g., “you” or “I” was changed to “he/she”. For all measures, increasing values indicate increasing amounts of the construct being measured, except for vision and hearing. Although psychometric data for many of the measures has been published, reliability data for the dependent variable measures are not described, because study-specific, test-retest intraclass correlational coefficients (ICCs) were calculated for a subsample of 20 subjects. We only included measures with ICCs ≥ 0.8 , as noted in Appendix 7, for analyses in the study.

Person Variables. We collected medical and demographic information including age, sex, country of origin, diagnoses, resident length of stay in the nursing home, smoking status (as these residents were required to go outside to smoke) (yes/no), and status as a veteran (as they were able to receive equipment via the Department of Veterans Affairs) (yes/no) from the subjects, proxies, or the subject’s medical chart.

We collected financial information, as residential care facilities in British Columbia are not all inclusive, and residents are expected to pay for some participation related expenses, such as price of admission and cost of meals during outings (Harris, 2005). We used daily room rate as a surrogate for annual income, as this rate is determined based on the resident’s annual income after taxes.

Pain has been noted to interfere with participation in activities among residents (Cadogan et al., 2008). We measured pain was using a single question from the SF-12, which measured pain interference on an ordinal five-category scale (Jenkinson et al, 1997).

Previous studies have determined that depression negatively affects activity participation (Voelkl et al., 1995) and subjective well-being (Patrick et al., 2000). We therefore measured symptoms of depression, using the either the 15 item Geriatric Depression Scale (D’Ath, Katona, Mullan, Evans, & Katona, 1994) or the 15 item proxy version (Brown & Schinka, 2005). For question 9, we replaced the word “home” with “nursing home” to ensure clarity. A GDS scores above the cutoff score of five indicates significant depressive symptoms on the measure (D’Ath et al., 1994).

Cognitive ability has been associated with social participation (Schroll et al., 1997) and quality of life (Chung, 2004), and we measured it with the Standardized Mini-Mental State Exam (SMMSE; Molloy, 1999).

Functional ability has been associated with engagement in activity (Kolanowski et al., 2006; Schroll et al., 1997) and quality of life (Edelman et al., 2005); and we measured it using

the Functional Independence Measure (FIM; Keith, Granger, Hamilton, & Sherwin, 1987). We omitted Item 11, bath transfer, as household bathtubs were not present in these facilities.

Vision and hearing problems have been associated with decreased social engagement among residents (Resnick et al., 1997). We measured vision using a one item, five-point ordinal scale from the minimum data set (MDS) (2.0) (Centers for Medicare & Medicaid Services, 2009). We measured hearing using a one item, four-point ordinal scale from the MDS (2.0). For these scales, measurement of these senses is operationalized based on functional ability.

Health status has been identified as a predictor of quality of life in residential care research (Patrick et al., 2000) and we measured this construct using the 18-item Comorbidity Index (CMI; Groll, To, Bombardier, & Wright, 2005), the general five-point scale, health question from the SF-12 (Jenkinson et al, 2007), and number of regularly scheduled medications (excluding vitamins and as needed medications).

Wheelchair-related Variables. Wheelchair-related data included the broad category of wheelchair (power or manual), ownership (resident or facility) and use of more than one wheelchair (yes or no).

Given that having a properly prescribed wheelchair has been shown to influence health-related social functioning (Trefler et al., 2004), need for seating intervention was measured using the Seating Identification Tool (SIT; Miller, Miller, Trenholm, Grant, & Goodman, 2004). A score of two or higher indicates the need for seating intervention.

Wheelchair skills represent a resident's capacity to propel and operate his or her wheelchair (releasing brakes, remove footrests etc.) and were measured using the Wheelchair Skills Test – Questionnaire (WST-Q; Mountain, Kirby, & Smith, 2004). We used version 3.2 of the WST-Q for this study as this enabled data to be collected on manual and power mobility users.

Wheelchair issues. We summed together five dichotomous variables: 1) inability to release the seat belt, 2) use of a lap tray, 3) sitting in a wheelchair not capable of self-propulsion 4) inability to release both breaks and 5) sitting on a transfer sling to create a variable called wheelchair issues (1 point for each yes response, 0-5= range). This variable included primarily restraint related variables that were not included in the SIT.

Satisfaction with wheelchair-related activity performance. We measured satisfaction with performance of subject-selected activities using a wheelchair with the Wheelchair Outcome Measure (WhOM; Mortenson, Miller, Miller-Polgar, 2007).

We collected additional information on length of time using a wheelchair (in months), and hours per day spent sitting in a wheelchair, the presence of a seat belt (yes/no).

Environmental Variables. We measured environmental barriers to participation using the Craig Hospital Inventory of Environmental Factors (CHIEF; Whiteneck et al., 2004), excluding items from the work/school domain as these were not applicable to most residents. We replaced the word “home” with “facility” in questions 2, 12, 15, and 18 to prevent ambiguity. The CHIEF includes four domains: attitudes, services/assistance, physical structure, and policies.

We measured facility satisfaction using the short form of the Resident Satisfaction Questionnaire (RSQ), which consists of 26 four-choice ordinal items (Chou, Boldy, Lee, 2002).

Additional environmental variables included distance from the resident’s room to the nursing station in meters, the subject’s number of roommates, and frequency of visits by friends or family over the course of week as a measure of social support.

Descriptive facility information included the direct care staffing ratio (hours of funded care per resident per day), occupational therapist, activity/recreational worker, and physiotherapist FTE (per 100 residents), adoption of the Eden alternative (yes/no), policy of least restraint (yes/no), provides only basic wheelchairs (yes/no), and power wheelchairs allowed (yes/no).

Personal/Wheelchair/Environmental Variables. As indicated in chapter 4, mobility represented a variable that was predicted by personal, wheelchair-related, and environmental factors and was therefore described outside the three domains of the MPT model as a hybrid variable. We measured mobility using the Nursing Home Life Space Diameter Measure (NHLSD; Tinetti & Ginter, 1990). The NHLSD is a four-item questionnaire that measures the extent, quality (independent versus dependent) and frequency of mobility of long-term care residents during the preceding two weeks. We used the NHLSD total score for the analyses.

Dependent Variables

The Late Life Function and Disability Instrument: Disability Component (LLDI; Jette et al., 2002) is a 16-item tool that measures participation in social roles by asking about the frequency of participation and the extent of limitation that respondents experience for 16 activities. We modified four questions to facilitate use in a residential care setting. We changed question number 5 (“Working at a volunteer job outside your home”) to “Helping out as a volunteer in the facility.” For question 8, which asks about “taking care of the inside of your home,” we changed the word “home” to “room.” For question 11, which asks about “inviting people into your home for a meal or entertainment” we changed the word “home” to “facility.”

For question 6, which asks about taking part in active recreation, we changed the examples provided from “This may include bowling, golf, tennis, hiking, or jogging” to, “This may include wheelchair bowling or swimming,” to reflect recreation activities more common in the facilities studied. We used frequency of participation as the dependent variable in the analyses because it is a more objective measure of participation than perceived limitation. Validity testing found the frequency and limitations scores for the tool could differentiate subjects assigned to four functional levels (Jette et al.).

We measured satisfaction with life using the Satisfaction with Life Scale, a five-item instrument that measures respondent’s appraisals of their general, rather than domain specific, quality of life (Diener, Emmons, Larsen, & Griffin, 1985). A review found the measure was moderately correlated ($r=0.45$ to 0.82) with other measures of life satisfaction in 11 studies and was negatively associated correlated with depression and neuroticism (Pavot & Diener, 1984).

Data Collection

The SMMSE was the first measure administered. All subsequent, nonrespondent completed measures were administered in a random order to minimize order bias. Data for the SIT, WST-Q, and FIM were collected through standardized procedures that involved a combination of observations by the raters, subject responses, information from staff and data from the resident’s chart. At the end of data collection, hearing and vision items from the MDS and CMI were completed by the raters. Total administration time for the measures was approximately two hours.

Data were collected by raters who were formally trained on all the measures used in the study. Using data from a sample of ten self-responders and ten proxy subjects, interrater reliability was determined for the SIT, FIM, and WST-Q and test-retest reliability was determined for all other measures. For test-retest reliability, measurements were taken on two occasions over a period of two weeks ($M=13.8$ days).

Analysis

We used multiple hierarchical linear regression modeling to address the study objectives. We screened data prior to analysis by double checking data entry for 30% of records and identifying scores that were outside their permissible range (e.g., negative ages, dichotomous ratings with a 3rd value etc.). We expressed continuous variables, such as SWLS and LLDI scores, as means and described categorical variables as proportions. For the WST-Q, if a subject was unable to indicate if a skill was performed, this skill was awarded a score of “0.” Diagnostic procedures were used to test that the necessary assumptions for the following statistical

techniques were not violated beyond the tolerance of the approach. We used independent samples *t* tests to identify significant differences ($p \leq 0.05$) between proxy and self-responding subjects for continuous variables. We used chi-square tests to identify significant differences in distributions between proxy and self-responding subjects for nominal variables. We used independent samples *t* tests to identify significant differences in mean scores of dependent variables for dichotomous independent variables including sex, smoking, non English speaking country of birth, owns wheelchair, use of a power chair, W/C issues >1 . We used ANOVA to compare differences in dependent variables between sites. We used Pearson or Spearman correlations to explore the associations between dependent variables and continuous independent variables depending on the distributions of the variables.

To deal with concerns about combining data from proxy and nonproxy sources, the proxy and nonproxy data were analyzed separately and, as a result, four, parsimonious hierarchical regression models were created (2 samples x 2 outcomes (LLDI and SWLS) = 4 models). The variables entered into each regression model were based on the plausibility of the relationship, previous published evidence of a relationship between variables and statistical selection by using bivariable correlations of $r > 0.2$. When continuous variables included only a single item or demonstrated substantial skew, we dichotomized them for entry into regression models based on published or statistical cut points. When possible collinearity was identified (intercorrelations > 0.70 between independent variables), the variable with the highest correlation with the dependent variable was selected for the regression model. To explore the influence of wheelchair-related variables on participation and life satisfaction and based on the MPT model, we entered wheelchair variables first into a hierarchical regression model. We entered personal and environmental together in the second step. We only entered WhOM scores into the quality of life regression model, as we did not consider this variable to be a predictor of participation. We entered combined wheelchair/personal/environmental variables like the NHLSD and LLDI that met the variable inclusion criteria into the participation regression models in a final step. Similarly, we considered NHLSD scores and LLDI scores for entry into a final step of the life satisfaction models. When cases had standardized residuals more than 3 standard deviations from the mean, we considered them for removal from the regression models (Kleinbaum, Kupper, Muller, & Nizam, 1998).

Results

Facility surveys indicated that the 11 facilities had a direct staffing ratio of 2.60 (SD=0.48), and 0.68 (SD=0.40) occupational therapists, 0.55 (SD=0.33) physiotherapists, and 2.31

(SD=1.54) activity workers/ recreation staff per 100 residents. All facilities had a least restraint policy, seven (64%) had adopted the Eden alternative, four (36%) allowed scooters and ten (91%) allowed the residents to use power wheelchairs. Mean SWLS scores did not differ significantly between facilities for self-responding subjects ($F=.991$, $p=0.454$) or proxy subjects (excluding site 6 as it only had two proxy respondents) ($F=1.947$, $p=0.054$). There was a significant difference between facilities for proxy LLDI frequency scores ($F= 2.962$, $p=0.004$) (also excluding site 6) but not for self-responding subject scores ($F= 1.773$ $p=0.071$). Post hoc analysis found site 3 had significantly lower LLDI frequency scores for proxy subjects than site 5. No significant differences were noted between the eight public facilities and three others (one private and two non-profit) in terms of their resident's LLDI frequency ($T=1.38$, $p=.169$) and satisfaction with life scores ($T=.124$, $p=.901$).

Fifty-five percent of those who we approached consented to take part in the study. The frequencies of nominal variables and central tendencies of continuous variables for the 149 self-responding and 119 proxy subjects who participated in the study are presented in Table 5.1. Most surrogate respondents for proxy subjects were family members (66.7%). Other surrogate respondents for these subjects included staff members (26.7%), staff and family members together (2.5%), paid companions (3.3%), and friends (0.8%).

Most self-responding subjects were women (64%) and a small proportion (16%) drove a power wheelchair. Most proxy subjects were women (76%), but only one (1%) drove a power wheelchair. Thirty-nine percent of self-responding subjects and sixty-nine percent of proxy subjects had GDS scores above the cutoff point indicating significant depressive symptoms on the measure. We dichotomized eight continuous variables for regression analysis and their cut points are indicated below. We dichotomized vision and health as they were single items scales with a range of values <5 . We dichotomized the number of family visits, length of wheelchair use, number of wheelchair issues and three CHIEF subscale scores because of significant skew.

Participation Frequency

Self-responding subjects had significantly higher LLDI frequency scores if they used a wheelchair for 12 months or more ($T=2.32$, $p=0.022$), experienced one or more wheelchair issues ($T=2.16$, $p=0.032$) had CHIEF attitude and service scores of three or more ($T=2.41$, $p=0.017$), had CHIEF physical and structure scores of 3 or more ($T=4.53$, $p<0.001$), or had CHIEF policy scores of more than one ($T=2.92$, $p=0.004$). Proxy subjects had significantly lower LLDI frequency scores if they experienced one or more wheelchair issues ($T=5.94$, $p<0.001$). The best binary cut point for visits for proxy subjects ($n=5$ visits per weeks) was not significant ($T=1.64$, $p=0.103$). Not reported in Table 5.1, a substantial number of subjects rarely took part in organized physical or social activities. Among self-responding subjects, 25.2% never or rarely took part in regular fitness programs and 29.5% never or rarely took part in organized social activities. Among proxy subjects, these percentages were 37.3% and 43.2% respectively. Proxy subjects had significantly lower LLDI frequency scores ($T=10.37$, $p<0.001$) than self-responding subjects.

Correlation matrices for continuous independent and dependent variables for self-responding and proxy subjects are presented in Appendixes 10 and 11. There was a significant negative correlation between depression and LLDI frequency scores for proxy and self-responding subjects. LLDI frequency scores were strongly correlated with NHLSD and FIM total scores for proxy subjects, but these correlations were more moderate for self-responding subjects. CHIEF scores, hours per day sitting in the wheelchair, and length of wheelchair use were significantly and positively correlated with LLDI frequency scores for self-responding subjects, but not for proxy ones. Visits were significantly correlated with LLDI frequency scores for proxy subjects, but not for self-responding subjects.

The next two tables present the results of the regression models for proxy and self-responding subjects in terms of their frequency of participation. We did not identify any outliers that had standardized residuals >3 standard deviations from the mean during the analyses, so no cases were removed.

The regression model of LLDI frequency scores for the self-responding subjects is presented in Table 5.2. In the final model, fewer depressive symptoms (GDS) and physical environmental barriers (CHIEF subscale) were significant predictors of participation frequency with standardized beta scores ≥ 0.271 . Surprisingly, the perception of physical environmental barriers was a positive predictor of frequency of participation. Mobility, policy environmental barriers and hours per day sitting in a wheelchair were significant at the $p=0.07$ to 0.08 level.

Other wheelchair-related factors were not significant in the final model. The final model accounted for 33% of variance in frequency of participation scores.

The regression model of LLDI frequency scores for proxy subjects is presented in Table 5.3. As no significant cut point for visits could be determined, this variable was not included in the regression model. Because of collinearity among wheelchair issues as a binary variable, WST-Q, and FIM scores, only the latter variable, the strongest bivariable correlation, was included in the regression analysis. Therefore, we did not enter any wheelchair-related variables into the regression model. In the final model, functional status, cognition and mobility were significant predictors of LLDI frequency ($p \leq 0.05$); and depression was significant at the $p = 0.054$ level. The final model accounted for over half of the variance in frequency of participation.

Life Satisfaction

Self-responding subjects had significantly higher SWLS scores if their health was very good or excellent (cut point ≥ 3) ($T = 2.46$, $p = 0.015$). Proxy subjects had significantly lower life satisfaction if they experienced one or more wheelchair issues ($T = 2.68$, $p = 0.009$) and significantly higher life satisfaction if their health was very good or excellent ($p = 0.005$). Proxy subjects had lower SWLS scores than self-responding subjects, and this difference was almost statistically significant ($T = 1.95$, $p = 0.052$).

As noted in Appendixes 10 and 11, SWLS scores were negatively correlated with depression and positively correlated with health and facility satisfaction for self-responding and proxy subjects. For proxy subjects SWLS scores were also positively correlated with FIM motor scores, CHIEF scores, wheelchair skills scores, NHLSD scores, LLDI frequency scores and WhOM scores.

The regression model of SWLS scores for self-responding subjects is presented in Table 5.4. No wheelchair-related variables met our inclusion criteria. Health, depression, and facility satisfaction were the only variables that met our variable selection criteria, and the latter two were significant predictors of satisfaction with life. Depression and facility satisfaction had standardized beta scores of -0.39 and 0.19 respectively. This model accounted for 21% of the variance in SWLS scores among self-responding subjects.

The regression model of SWLS scores for proxy subjects is presented in Table 5.5. Because of collinearity between the FIM and WST-Q, only the latter was included in the regression analysis. Depression, comorbidity, and satisfaction with attainment of wheelchair-related participation goals were significant predictors ($p \leq 0.05$) of SWLS scores. This model accounted for 36% of the variance in SWLS scores among self-responding subjects.

Overall, the regression models accounted for greater amounts of variance in frequency of participation and satisfaction with life among proxy subjects as compared to self-responding subjects. Additionally, we explained more variance for the frequency of participation compared to life satisfaction.

Discussion

This is one of the few studies to explore the predictors of participation frequency and life satisfaction among self-responding and proxy residents who use wheelchairs as their primary means of mobility.

Participation Frequency

Although some studies have looked at factors associated with the frequency of engagement in facility activities (Voelkl et al., 1995; Resnick et al, 1997), few studies have explored the predictors of the frequency with which residents engage in activities more generally. Although normative data among facility residents are not available for the LLDI, scores from the present sample were similar to findings from subjects in other residential care settings. For example, baseline data from a study of 682 residents, capable of goal setting, found that they had had a mean LLDI frequency score of 37.7 (SD=6.3) (Kerse et al., 2008), which is very similar to the mean scores from self-responding subjects in our study. Although the proportion of residents rarely involved in physical and social activities is comparable with previous research (Gottesman & Bourestom, 1974; Ice, 2002; Shore, Lerman, Smith, Iwata, DeLeon, 1995), it is cause for concern because low levels of participation may contribute to feelings of boredom (Slama & Bergman-Evans, 2000). Differences in participation between proxy and self-responding subjects are in keeping with previously published, nonwheelchair-specific research, as lower levels of activity participation have been reported among residents with dementia and cognitive impairments (Chung, 2004; Kolanowski et al., 2006; Perrin, 1997; Schroll et al., 1997; Voelkl et al., 1995). The differences in LLDI scores between different facilities among proxy subjects is reminiscent of differences in activity program participation that have been described between facilities (Voelkl et al., 1995), but it may also reflect the nonrandom nature of the sample.

There were three significant predictors of participation frequency among self-responding subjects. Depression has previously been identified as a predictor of activity program participation among residents (Voelkl et al., 1995), and the inverse relationship between depression and participation is logical. Our preliminary qualitative research suggested that institutional and societal barriers limit participation among residents; but counterintuitively, self-

responding subjects who scored above 3 on the physical structure domain of the CHIEF (i.e., more perceived barriers), which covers areas such as accessibility, natural environment, noise and computer access, had significantly higher levels of participation than those with lower scores (i.e., few perceived barriers). Likewise, a score above one on the policies domain of the CHIEF approached significance ($p=0.083$) for predicting participation among self-responding subjects in the regression model. These findings may indicate that, through their engagement in activities, self-responding subjects are better able to identify the environmental barriers to participation that they encounter and to overcome them successfully. Similarly, Whiteneck et al. (2004) found that individuals with spinal cord injuries who identified more policy barriers on the CHIEF had significantly higher levels of participation when all variables were entered into a final regression model. In contrast, as would be expected for self-responding subjects, there was a significant positive relationship between perceived participation limitations and environmental barriers. Mobility, as measured using the NHLSD, approached significance ($p=0.072$) as a predictor of participation. This finding echoes research by Hoenig et al. (2003) that found mobility limitations were associated with decreased participation among community-dwelling wheelchair users.

Four variables were significant predictors of participation among proxy subjects. Cognitive status and depression have previously been identified as predictors of participation in activity programs (Voelkl et al, 1995). In keeping with previous research (Kolanowski et al., 2006; Schroll et al., 1997), functional ability was independently associated with participation frequency, which suggests that individuals who require less assistance are likely to participate more often. We found mobility to be a significant independent predictor of participation among proxy subjects. Research conducted during the development of the NHLSD found mobility was moderately correlated with social participation among residents ($r=0.565$) (Tinetti & Ginter, 1990), which is almost identical to the value we found for the total sample in Appendix 9 ($r=0.56$). With the addition of more variables, our final model was able to explain over half of the variance in participation among proxy subjects.

Life Satisfaction

Normative data are not available for the SWLS, but a random sample of 129 residents with little or no cognitive impairment had average SWLS scores of 24.8 (SD=6) (O'Connor & Vallerand, 1994), which is approximately half a standard deviation higher than for self-responding subjects in our study. In terms of life satisfaction, surrogate respondents have been noted to indicate residents with cognitive impairment have lower levels of quality of life than residents who self-respond (Edelman et al., 2005); but no significant differences in SWLS scores were noted between proxy and self-responding subjects in our study.

We were able to explain only a modest amount of variance in SWLS scores among self-responding subjects. Depression was a significant predictor of subjective well-being in this population, consistent with Patrick et al. (2000). In contrast, functional status was not associated with satisfaction with life in this sample of residents. Although Patrick et al. (2000) explained 52% of adjusted R^2 among self-responding residents using similar variables, our lower level of explained variance may be attributed to the different independent and dependent measures used in that study. Environmental barriers, measured using the CHIEF, have been identified as significant predictors of life satisfaction in individuals with spinal cord injury (Whiteneck, Meade, Dijkers et al., 2004), but were not significantly correlated with life satisfaction scores in the current study. Diener, Suh, & Oishi (1997) have previously identified the limited influence of demographic variables such as age and income on life satisfaction. It may be that wealth only influences satisfaction with life when basic physical needs are not being met due to limited income (Diener et al.). The lack of influence of variables such as functional independence and comorbidity suggests that residents may have undergone a response shift as the criteria they used to evaluate their lives changed over time, which has been found in other populations (Sprangers and Schwartz, 1999).

We identified three variables as significant predictors of life satisfaction among proxy subjects. As with self-responding subjects, depression was a significant predictor of life satisfaction. Satisfaction with performance of activities using a wheelchair (measured using the WhOM), rather than participation frequency, was also a significant predictor of life satisfaction. This finding is reminiscent of research that has identified higher correlations between satisfaction with participation and quality of life than participation accomplishment in individuals with disabilities living in the community (Levasseur, Desrosiers & Noreau, 2004). Edelman et al. (2005) found that disease severity and quality of life scores were significantly correlated for proxy subjects. Comorbidity might act as a predictor for life satisfaction scores, as surrogate

respondents use this information as a basis for inferring life satisfaction scores for residents they are representing.

The association between wheelchair-related factors, participation, and satisfaction with life outcomes was not as clear-cut as we anticipated. Among self-responding subjects, hours per day in wheelchair was the only variable that approached a significance value of $p \leq 0.05$ in predicting participation ($p=0.076$). It seems logical that the more time residents spend in their wheelchairs, the greater opportunities they have for participation, as they are probably in bed otherwise. Among proxy subjects, collinearity among wheelchair skills, wheelchair issues and functional independence scores prevented us from entering all of these variables into the regression model to consider their influences independently; but FIM total scores had the highest correlations with mobility ($r=0.596$ versus $r=0.436$ for WST-Q for subjects included in the regression model), which suggests these wheelchair-related variables are less important than functional independence scores. No wheelchair-related variables demonstrated a significant association with life satisfaction scores among self-responding residents. Only satisfaction with wheelchair-related participation, as measured by the WhOM was a significant predictor of life satisfaction among proxy subjects; however, we had hypothesized that wheelchair-related variables would be more strongly related to participation outcomes. This finding may also reflect an element of social desirability bias as surrogate respondents may have inadvertently tried to provide responses they felt the researchers wanted. Some of the influence of wheelchair factors may have been obscured by the addition of NHLSD scores to the regression models, which were significant predictors or neared significance for proxy and self-responding subjects respectively. As noted in chapter 4, wheelchair skills were the most important predictors of mobility scores among proxy subjects and self-responding subjects in terms of their standardized beta weights and therefore may contribute to the effect this variable has on participation.

Overall, we were able to account for more variance in frequency of participation and life satisfaction among proxy subjects than among self-responding subjects and more variance in frequency of participation than life satisfaction. Given reduced opportunities for participation among proxy subjects, it is possible that this outcome can be better modeled for these residents with the variables that we collected in our study. For example, it may be easier to model participation in predominately facility-based activities that are done by proxy subjects. It also seems possible that proxy raters use similar criteria to evaluate resident life satisfaction, whereas variation in life satisfaction scores among self-responding subjects may be more individualistic. The amount of variance in life satisfaction scores, in comparison to participation frequency, is

not unexpected, given the variety of factors that contribute to evaluations of life satisfaction and given the fact that we did not collect data on nonmodifiable, dispositional traits such as optimism or extroversion, which have been shown to be strongly correlated with SWLS scores (Diener, Suh, and Oishi, 1997).

The proportion of self-responding subjects with depressive symptoms is in keeping with previously reported findings. A study of a random sample of residents from a random sample of six nursing homes in New York State found significant depressive symptomatology in 44.2% of residents with a 95% confidence interval of 38.2% to 50.3% (Teresi, Abrams, Holmes, Ramirez & Eimicke, 2001). The higher prevalence of depressive symptoms among proxy subjects is in accordance with earlier research on the GDS, which found surrogate respondents give significantly higher scores than self-respondents (Brown & Schinka, 2005). The prevalence of depression among subjects, however, is still a concern, especially given low levels of depression recognition among staff in these settings (Teresi et al., 2001).

Strengths and Limitations

Strengths of the research include the large sample size, high reliability of measures included in the study, limited amount of missing data and inclusion of personal, wheelchair-related and environmental variables in the same study. Although random sampling was attempted, the response rate indicates that subjects more closely represent a sample of convenience. We modified several of the measures from their original format, which may have affected their validity. As well, proxy versions and validity data were unavailable for many of the measures. However, interclass correlations coefficients from those measures that were included in the analyses indicate high levels of reliability. A more residential-care specific measure may have provided a better measure of participation for this population; however, we were unable to identify any such measures that were not diagnosis specific (for residents with dementia (i.e., the Patient Activity Scale=Alzheimer's disease (Albert et al., 1996)). As well, visits as a measure of social support did not include information about the quality of these interactions or about other forms of contact such as telephone calls or mail. As we awarded subjects a score of 0 if they could not indicate they could perform a skill, this likely created a conservative estimate of their wheelchair skills. Results from most of the measures were based on self or proxy report, which may be affected by recall or social desirability biases. Observational measures of participation frequency and environmental barriers may have produced different results.

Future work

Although this study did not reveal a strong relationship between wheelchair-related factors and participation and quality of life, the findings of the study are not definitive and might reflect the measures used to capture participation and life satisfaction. Furthermore, the cross-sectional nature did not allow the impact of changes in wheelchair-related factors to be addressed. Additional research could further explore the relationship between mobility and participation and the impact of institutional and other environmental factors, on participation and satisfaction with life. With an increased number of subjects, structural equation modeling could be used to explicate the relationship among mobility, participation, and life satisfaction. In light of the prevalence of depressive symptoms among subjects and the association between depression and participation and life satisfaction, this represents a potential area for future intervention research. Intervention studies could determine whether treatment for depression increases participation and quality of life among residents. For example, one might also explore if a participation intervention, that is, engaging residents in activities of interest to them, can lift depressive symptoms and enhance health/life satisfaction. Studies could also examine whether changes to the facility environment that promote participation would affect depression and life satisfaction as some work on the Eden alternative has suggested (Bergman-Evans, 2004; Thomas, 1994).

Conclusion

This is one of the few studies to explore the predictors of participation and life satisfaction among long-term care residents who use wheelchairs as their primary means of mobility. Wheelchair-related variables did not have a consistent effect across proxy and self-responding residents when looking at the models that predict participation and life-satisfaction. Depression, which was common among residents, was a significant predictor of participation among self-responding subjects and life satisfaction among self-responding and proxy subjects, which suggests this represents an area of future study.

Table 5.1: Characteristics of Self-responding and Proxy Subjects

Characteristic	self-responding		proxy	
Personal Factors				
Continuous	Mean or N	SD or (%)	Mean or N	SD or (%)
Age (years) ^a	82.64	8.78	86.03	8.06
Comorbidity count	3.24	1.97	2.88	1.89
Daily Rate (\$) ^b	39.85	14.84	46.12	17.1
FIM Motor ^a	44.03	16.12	23.05	12.21
FIM Total ^a	75.49	17.44	38.39	17.97
GDS ^a	3.99	3.00	6.5	3.64
Health ^a	2.11	1.10	1.67	1.0
Length of Stay (m)	33.34	42.49	33.12	28.99
Meds ^b	8.49	3.33	7.28	3.28
SMMSE ^a	23.91	4.11	4.67	5.52
Dichotomous				
English COB (Yes)	125	(83.9%)	98	(82.4%)
Sex (male) ^c	54	(36.2%)	29	(24.4%)
Smoker (yes) ^c	11	(7.4%)	1	(0.8%)
Vision (≥ 2)	25	(16.9%)	28	(23.9%)
Wheelchair-related Factors				
Continuous				
Hours in WC	8.83	3.87	8.96	3.36
Length of WC use ^d				
(m)	54.5	88.38	33.12	28.99
SIT	2.1	1.8	2.19	1.73
WhOM ^d	61.23	23.24	55.29	24.77
WST-Q ^a	0.41	0.17	0.15	0.15
Dichotomous				
Owns WC ^c	59	(39.6%)	29	(24.6%)
Power Chair ^e	23	(15.5%)	1	(0.8%)
	Mean or N	SD or (%)	Mean or N	SD or (%)

Characteristic	self-responding		proxy	
WC issues (≥ 1) ^e	33	(23.6%)	85	(72.0%)
Environmental Factors				
CHIEF attitude	2.66	5.01	2.03	3.57
CHIEF services	5.61	7.23	5.24	6.96
CHIEF physical	4.24	5.42	4.12	4.85
CHIEF policies	1.62	3.73	1.43	2.88
RSQ total ^d	46.15	11.01	49.56	11.64
Visits ^b	2.83	2.94	4.06	3.58
Mobility				
NHLSD total score ^a	49.11	20.09	31.13	12.56
Dependent Variables				
Participation				
LLDI frequency ^a	37.65	9.3	26.63	7.63
Quality of Life				
SWLS total	21.91	7.07	20.29	6.25

CHIEF = a= independent samples t-test $p \leq 0.001$, b= independent samples t-test $p \leq 0.01$, c= X^2 $p \leq 0.05$, Craig Hospital Inventory of Environmental Factors, d=independent samples t test $p \leq 0.05$, e= X^2 $p \leq 0.001$, FIM = Functional Independence Measure, GDS=Geriatric Depression Scale NHLSD = Nursing Home Life Space Diameter, LLDI = Late Life Function and Disability Instrument: Disability Component, m= months, RSQ = Resident Satisfaction Questionnaire, SMMSE = Standardized Mini-Mental State Examination, SD= Standard Deviation, SWLS= Satisfaction with Life Scale WhOM=Wheelchair Outcome Measure, WST-Q = Wheelchair Skills Test Questionnaire

Table 5.2: Regression Analysis to Identify Factors Associated with Participation Frequency for Self-responding Subjects (N=143)

	Wheelchair Factors					Personal and Environmental Factors					Wheelchair/Personal/Environmental Factors				
	β	<i>SE</i>	S β	LB	UB	β	<i>SE</i>	S β	LB	UB	β	<i>SE</i>	S β	LB	UB
(Constant)	27.76	2.59		22.65	32.87	24.94	5.57		13.93	35.95	24.47	5.52		13.54	35.40
WST-Q	14.34	4.53	.28	5.39	23.30	6.98	4.73	.13	-2.37	16.33	2.76	5.23	.05	-7.58	13.11
Hours in WC	.38	.19	.16	.00	.76	.35	.18	.15	.00	.70	.31	.18	.13	-.03	.66
Length of WC use > 12m	1.53	1.80	.07	-2.02	5.08	.50	1.64	.02	-2.75	3.75	.61	1.63	.03	-2.61	3.84
WC issues	-1.35	1.74	-.07	-4.80	2.09	-.82	1.60	-.04	-3.99	2.34	-1.01	1.59	-.05	-4.15	2.13
FIM						.06	.04	.11	-.03	.14	.05	.04	.10	-.03	.14
GDS						-.91	.23	-.30	-1.36	-.46	-.87	.23	-.29	-1.32	-.43
SMMSE						.09	.18	.04	-.27	.44	.06	.18	.03	-.29	.42
CHIEF policies > 1						2.90	1.62	.15	-.31	6.11	2.81	1.61	.14	-.37	6.00
CHIEF attitudes > 3						1.55	1.65	.08	-1.70	4.81	1.56	1.63	.08	-1.67	4.79
CHIEF physical > 3						4.85	1.43	.27	2.03	7.67	4.84	1.41	.27	2.05	7.64
NHLSD											.07	.04	.16	-.01	.15
Cumulative Adj r^2	.13					.32					.33				
Adj r^2 change per step	.13					.19					.01				

Abbreviations: Adj. = adjusted *SE* = Standard Error, S β = Standardized β , LB = lower 95% confidence interval for β , UB = upper 95% confidence interval for β , CHIEF = Craig Hospital Inventory of Environmental Factors, FIM = Functional Independence Measure, GDS=Geriatric Depression Scale NHLSD = Nursing Home Life Space Diameter, SMMSE = Standardized Mini-Mental State Examination, WC=wheelchair WST-Q = Wheelchair Skills Test Questionnaire, **bold**= significant $p \leq 0.05$

Table 5.3: Regression Analysis to Identify Factors Associated with Participation Frequency for Proxy Subjects (N=111)

	Personal and Environmental Factors					Wheelchair/Personal/Environmental Factors				
	β	<i>SE</i>	S β	LB	UB	β	<i>SE</i>	S β	LB	UB
(Constant)	19.12	2.09		14.98	23.26	15.06	2.18		1.73	19.38
FIM total	.20	.04	.44	.12	.27	.12	.04	.26	.04	.19
GDS	-.41	.15	-.20	-.72	-.11	-.29	.15	-.14	-.58	.01
SMMSE	.20	.11	.14	-.03	.42	.29	.11	.20	.07	.50
Vision ≥ 2	-1.98	1.32	-.11	-4.60	.64	-1.50	1.24	-.08	-3.95	.96
Comorbidity	.44	.31	.10	-.18	1.05	.30	.29	.07	-.28	.87
CHIEF Physical ≥ 3	2.00	1.15	.13	-.29	4.29	1.14	1.10	.07	-1.03	3.33
NHLSD						.21	.05	.34	.111	.32
Cumulative Adj. r^2		.44					.51			
Adj. r^2 change per step		.44					.07			

Abbreviations: *SE* = Standard Error, S β = Standardized β , LB = lower 95% confidence interval for β , UB = upper 95% confidence interval for β , CHIEF=Craig Hospital Inventory of Environmental Factors. FIM = Functional Independence Measure, GDS = Geriatric Depression Scale, NHLSD=Nursing Home Life Space Diameter Measure, SMMSE=Standardized Mini Mental Status Exam, **bold**= significant $p \leq 0.05$

Table 5.4: Regression Analysis to Identify Factors Associated with Life Satisfaction of Self-responding Subjects (N=146)

	β	<i>SE</i>	$S\beta$	LB	UB
(Constant)	2.07	2.63		14.87	25.27
GDS Total	-.91	.19	-.39	-1.29	-.54
Health \geq 3	-.16	1.17	-.01	-2.48	2.16
RSQ total	.12	.05	.19	.02	.22
Cumulative Adj r^2			.21		

Abbreviations: *SE* = Standard Error, $S\beta$ = Standardized β , LB = lower 95% confidence interval for β , UB = upper 95% confidence interval for β , GDS=Geriatric Depression Scale, RSQ= Resident Satisfaction Questionnaire, **bold**= significant $p \leq 0.05$

Table 5.5: Regression Analysis to Identify Factors Associated with Life Satisfaction of Proxy Subjects (N=110)

Steps	Wheelchair Factors					Other MPT Factors					Mobility and Participation				
	β	<i>SE</i>	S β	LB	UB	β	<i>SE</i>	S β	LB	UB	β	<i>SE</i>	S β	LB	UB
(Constant)	13.27	2.30		8.71	17.84	18.77	3.73		11.37	26.18	17.07	4.66		7.82	26.32
WST-Q	1.81	4.87	.26	1.16	2.46	5.23	4.56	.13	-3.81	14.28	4.61	4.78	.11	-4.87	14.08
WhOM satisfaction	.82	.24	.31	.35	1.29	.62	.22	.23	.19	1.05	.59	.22	.22	.15	1.03
WC Issues \geq 1	-.44	1.60	-.03	-3.62	2.73	-.54	1.44	-.04	-3.39	2.31	-.30	1.51	-.02	-3.29	2.70
GDS						-.58	.16	-.33	-.89	-.27	-.56	.16	-.32	-.88	-.24
Health \geq 3						1.07	1.31	.07	-1.52	3.67	1.05	1.34	.07	-1.62	3.72
Comorbidity						-.66	.26	-.20	-1.18	-.15	-.71	.27	-.21	-1.24	-.17
RSQ						.06	.05	.11	-.03	.15	.07	.05	.12	-.03	.16
CHIEF services \geq 1						-1.12	1.14	-.08	-3.37	1.14	-1.04	1.16	-.08	-3.34	1.26
NHLSD											.01	.05	.02	-.09	.11
LLDI											.04	.09	.05	-.14	.22
Cumulative Adj. r^2		.20						.37					.36		
Adj. r^2 change per step		.20						.17					-.01		

Abbreviations: *SE* = Standard Error, S β = Standardized β , LB = lower 95% confidence interval for β , UB =upper 95% confidence interval for β , CHIEF = Craig Hospital Inventory of Environmental Factors, GDS=Geriatric Depression Scale, LLDI=Late Life Function and Disability Instrument, Disability Component, NHLSD = Nursing Home Life Space Diameter, RSQ = Resident Satisfaction Questionnaire, WC=wheelchair, WhOM=Wheelchair Outcome Measure, WST-Q = Wheelchair Skills Test Questionnaire Scale, **bold**= significant $p \leq 0.05$

References

- Albert, S.M., Del Castillo-Castaneda, M., Sano, M, Jacobs, D., Marden, L., Bel, K. et al., (1996). Quality of life in patients with Alzheimer's disease as reported by patient proxies. *Journal of the American Geriatrics Society*, 44, 1342-1347.
- Barker, D.J., Reid, D., & Cott, C. (2004) Acceptance and meanings of wheelchair use in senior stroke survivors. *American Journal of Occupational Therapy*, 58, 221-230.
- Bergman-Evans, B. (2004). Beyond the basics. Effects of the Eden Alternative model on quality of life issues. *Journal of Gerontological Nursing*, 30, 27-34.
- Brown, L.M., & Schinka, J.A. (2005). Developmental and initial validation of a 15-item informant version of the geriatric depression scale. *International Journal of Geriatric Psychiatry*, 20, 911-918.
- Cadogan, M.P., Edelen, M.O., Lorenz, K.A., Jones, M., Yosef, J., Hascall, T., Simon, B., Harker, J.O., Ferrell, B., & Saliba, D. (2008). The relationship of reported pain severity to perceived effect on function of nursing home residents. *Journal of Gerontology*, 63A, 969-973.
- Castle, N.G., & Mor, V. (1998). Physical restraints in nursing homes: A review of the literature since the nursing home reform act of 1987. *Medical Care Research and Review*, 55, 139-170.
- Centers for Medicare & Medicaid Services (2009). MDS 2.0 Manual and forms. Downloaded March 10, 2009 from http://www.cms.hhs.gov/MinimumDataSets20/025_ManualsAndForms.asp#TopOfPage.
- Chou, S.C., Boldy, D.P., & Lee, A.H. (2002). Resident satisfaction and its components in residential aged care. *The Gerontologist*, 42, 188-198.
- Chung, J. C. C. (2004). Activity participation and well-being in people with dementia in long-term care settings. *Occupational Therapy Journal of Research*, 24, 22–31.
- D'Ath, P., Katona, P., Mullan, E., Evans, S., & Katona, C. (1994). Screening, Detection and Management of Depression in Elderly Primary Care Attenders. I: The Acceptability and Performance of the 15 Item Geriatric Depression Scale (GDS15) and the Development of Short Versions. *Family Practice*, 11, 260-266.
- Devitt, R., Chau, B., & Jutai, J. W. (2003). The effect of wheelchair use on the quality of life of persons with multiple sclerosis. *Occupational Therapy in Health Care*, 17, 63-79.
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment*, 49, 71-75.

Diener, E., Suh, E., & Oishi, S. (1997). Recent findings on subjective well-being. *Indian Journal of Clinical Psychology, 24*, 25-41.

Edelman, P., Fulton, B. R., Kuhn, D., & Chang, C. H. (2005). A comparison of three methods of measuring dementia-specific: Perspectives of residents, staff, and observers. *The Gerontologist, 45* Special Issue 1, 27-36.

Fiveash, B. (1998). The experience of nursing home life. *International Journal of Nursing Practice, 4*, 166-174.

Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*, 189-198.

Fuchs, R.H. & Gromak, P.A. (2003). Wheelchair use by residents of nursing homes: Effectiveness in meeting positioning and mobility needs. *Assistive Technology, 15*, 151-163.

Forward, J.A. (2000). The prevalence of wheelchair and seating intervention needs in long term care in London, Ontario. Unpublished master's project, University of Western Ontario, London, ON.

Gaugler, J.E. (2005). Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health, 9*, 105-118.

Ghusn, H. F., Hyde, D., Stevens, E. S., Hyde, M., & Teasdale, T. A. (1996). Enhancing life satisfaction in later life: What makes a difference for nursing home residents. *Journal of Gerontological Social Work, 26*, 27-47.

Gottesman, L. E., & Bourestom, N. C. (1974). Why nursing homes do what they do. *The Gerontologist, 14*, 501-506.

Groll, D.L., To, T., Bombardier, C., & Wright, J.G. (2005). The development of a comorbidity index with physical function as the outcome. *Journal of Clinical Epidemiology, 58*, 595-602.

Gubrium, J.F. (1975). *Living and dying at Murray Manor*. New York: St. Martin's Press.

Gueldner, S. H., Loeb, S., Morris, D., Penrod, J., Bramlett, M., & Johnston, L., & Schlotzhauer, P. (2001). A comparison of life satisfaction and mood in nursing home residents and community-dwelling elders. *Archives of Psychiatric Nursing, 15*, 232-240.

Harris, J. (2005). *Uncovering the cost of care: An examination of extra billing in BC's long-term care facilities*. Master's thesis, Simon Fraser University. Burnaby.

Herrington, C., Carrillo, H., & Blank, B.W. (2008). Nursing facilities, staffing, residents and facility deficiencies, 2001 through 2007. Department of Social and Behavioural Sciences, University of California, San Francisco, CA.

Hoening, H., Landerman, L.R., Shipp, K.M., & George, L. (2003). Activity restriction among wheelchair users, *Journal of the American Geriatric Society*, 51, 1244-1251.

Ice, G. H. (2002). Daily life in a nursing home: Has it changed in 25 years. *Journal of Aging Studies*, 16(4), 345-360.

Jenkinson, C., Layte, R., Jenkinson, D., Lawrence, K., Petersen, S., Paice, C., & Stradling, J. (1997). A shorter form health survey: can the SF-12 replicate results from the SF-36 in longitudinal studies? *Journal of Public Health Medicine*, 19, 179-186.

Jette, A.M., Haley, S.M., Coster, W.J., Kooyoomjian, J.T., Levenson, S., Heeren, T., & Ashba, J. (2002). Late life function and disability instrument: I. Development and evaluation of the disability component. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 57, M209-M216.

Kane, R.L., Bershadsky, B., Kane, R.A., Degenholtz, H.H., Lui, J., Giles, K., & Kling, K.C. (2004). Using resident reports of quality of life to distinguish among nursing homes. *The Gerontologist*, 5, 624-632.

Kasser, V., & Ryan, R. (1999). The relation of psychological needs for autonomy and relatedness to vitality, well-being, and mortality in a nursing home. *Journal of Applied Social Psychology*, 29, 935-954.

Kayser-Jones, J.S. (1981). *Old, alone, and neglected: Care of the aged in the United States and Scotland*. Berkley, CA: University of California Press.

Keith R.A., Granger, C.V., Hamilton, B.B., & Sherwin, F.S. (1987). The functional independence measure: A new tool for rehabilitation. *Advances in Clinical Rehabilitation*, 1, 6-18.

Kerse, N., Peri, K., Robinson, E., Wilkinson, T. von Randow, M., Kiata, L. et al. (2008). Does a functional activity programme improve function, quality of life, and falls for residents in long term care? Cluster randomised controlled trial. *British Medical Journal*, 337, 907-921.

Kleinbaum, D.G., Kupper, L.L., Muller, K.E., & Nizam, A. (1998). *Applied regression analysis and other multivariable methods*. Pacific Grove, CA: Cole Publishing Company.

Kolanowski, A., Buettner, L., Litaker, M., & Yu, F. (2006). Factors that relate to activity engagement in nursing home residents. *American Journal of Alzheimer's Disease and Other Dementias*, 21, 15-22.

Levasseur, M., Desrosiers, J., & Noreau, L. (2004). Is social participation associated with quality of life of older adults with physical disabilities? *Disability and Rehabilitation*, 26, 1206-1213.

McGuinn, K. K., & Mosher-Ashley, P. M. (2000). Participation in recreational activities and its effect on perception of life satisfaction in residential settings. *Activities, Adaptation and Aging*, 25, 77-86.

McGregor, M. J., Tate, R.B. Ronald, L.A., & McGrail, K.M. (2007). *Journal of Palliative Medicine*, 10, 1128-1136.

Miller, W.C., Miller, F., Trenholm, K., Grant, D., & Goodman, K. (2004). Development and preliminary assessment of the measurement properties of the seating identification tool (SIT). *Clinical Rehabilitation*, 18, 317-325.

Molloy, D. W. (1999). *The Standardized Mini-Mental Status Exam (SMMSE)*. New Grange Press, Troy, Ontario, Canada.

Mortenson, W.B., Miller, W.C., Boily, J., Steele, B., Odell, L. Crawford, E.M. & Desharnais, G. (2005). Perceptions of power mobility use and safety within residential facilities. *Canadian Journal of Occupational Therapy*, 72, 142-152.

Mountain, A.D., Kirby, R.L., & Smith, C. (2004). The wheelchair skills test, version 2.4: Validity of an algorithm-based questionnaire version. *Archives of Physical Medicine and Rehabilitation*, 85, 416-423.

O'Connor, B.P. & Vallerand, R.J. Motivation, self-determination, and person-environment fit as predictors of psychological adjustment among nursing home residents. *Psychology and Aging*, 9, 189-194.

Patrick, D.L., Kinne, S., Engelberg, R.A., & Pearlman, R.A. (2000). Functional status and perceived quality of life in adults with and without chronic conditions. *Journal of Clinical Epidemiology*, 53, 779-785.

Pavot, W. & Diener, E. (1993). Review of the satisfaction with life scale. *Psychological Assessment*, 5, 164-172.

Perrin, T. (1997). Occupational need in severe dementia: A descriptive study. *Journal of Advanced Nursing*, 25, 934-941.

Pettersson, I. Törnquest, K., & Ahlström, G. (2006). The effect of an outdoor powered wheelchair on activity and participation in users with stroke. *Disability and Rehabilitation: Assistive Technology*, 1, 235-243.

Post, M.W.M., de Witte, L.P., Schrijvers, A.J.P. (1999) Quality of life and the ICIDH: towards an integrated conceptual model for rehabilitation outcomes research. *Clinical Rehabilitation*, 13, 5-15.

Resnick, H.E., Fries, B.E., & Verbrugge, L.M. (1997). Window to their world: The effect of sensory impairments on social engagement and activity time in nursing home residents. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 52, S135-44.

Schroeder, J.M., Nau, K.L., Osness, W.H., & Potteiger, J.A. (1989). A comparison of life satisfaction, functional ability, physical characteristics, and activity level among older adults in various living settings. *Journal of Aging and Physical Activity*, 6, 340-349.

Schroll, M., Jonsson, P. V., Mor, V., Berg, K., & Sherwood, S. (1997). An international study of social engagement among nursing home residents. *Age and Ageing*, 26 Suppl 2, 55-59.

Shields M. (2004). Use of wheelchairs and other mobility support devices. *Health Reports*, 15, 37-41.

Shore, B.A., Lerman, D.C., Smith, R.G., Iwata, B.A., & Deleon, I.G. (1995). Direct assessment of quality of care in a geriatric nursing home. *Journal of Applied Behaviour Analysis*, 28, 435-448.

Slama, C.A., & Bergman-Evans, B. (2000). Boredom, loneliness and helplessness. A troubling triangle. *Journal of Psychosocial Nursing*, 38, 37-43.

Rust, K.L., & Smith, R.O. (2005). Assistive technology in the measurement of rehabilitation and health outcomes: a review and analysis of instruments. *American Journal of Physical Medicine and Rehabilitation*, 84, 780-793.

Smithers, J.A. (1990). A wheelchair society: The nursing home scene. *Journal of Aging Studies*, 4, 261-275.

Sprangers, M.A., & Schwartz, C.E. (1999). Integrating response shift into health-related quality of life research: a theoretical model. *Social Sciences and Medicine*, 48, 1507-1515.

Teresi, J., Abrams, R., Holmes, D., Ramirez, M., & Elmicke, J. (2001). Prevalence of depression and depression recognition in nursing homes. *Social Psychiatry and Psychiatric Epidemiology*, 36, 613-620.

Thomas, W. (1994). *The Eden alternative: Nature, hope and nursing homes*. New York: Eden Alternative Foundation.

Tinetti, M.E. & Ginter, S.F. (1990). The nursing home life-space diameter. A measure of extent and frequency of mobility among nursing home residents. *Journal of the American Geriatrics Society*, 38, 1311-1315.

Trefler, E., Fitzgerald, S.G., Hobson, D.A., Bursick, T. & Joseph, R. (2004). Outcomes of wheelchair systems intervention with residents of long-term care facilities. *Assistive Technology*, 16, 18-27

Vallerand, R.J., O'Connor, B.P., & Blais, M.R. (1989). Life satisfaction of elderly individuals in regular community housing, in low-cost community housing, and high and low self-determination nursing homes. *International Journal of Aging and Human Development*, 28, 277-283.

Voelkl, J.E., Fries, B.E., & Galecki, A.T. (1995). Predictor of nursing home residents' participation in activity programs. *Gerontologist*, 35, 44-51.

Vladeck, B.C. (2003). *Unloving Care* revisited: The persistence of culture. . *Journal of Social Work in Long-Term Care*, 2, 1-9.

Whiteneck, G.G., Harrison-Felix, C.L., Mellick, D.C., Brooks, C.A., Charlifue, S.B., & Gerhart, K.A. (2004). Quantifying environmental factors: A measure of physical, attitudinal, service, productivity, and policy barriers. *Archives of Physical Medicine and Rehabilitation*, 85, 1324-1335.

Whiteneck, G., Meade, M., Dijkers, M., Tate, D., Bushnik, T., & Forchheimer, M. (2004). Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 85, 1793-1803.

Zimmerman, S., Sloane, P.D., Williams, C.S., Reed, P.S., Preisser, J.S., Eckert, J.K., et al. (2005). Dementia care and quality of life in assisted living and nursing homes. *The Gerontologist*, 45, special issue 1, 133-146.

Chapter 6: Conclusion, Synthesis, and Recommendations for Future Research

This mixed-methods research project provided qualitative and quantitative insights into the lives of residents who use wheelchairs as their primary means of mobility. The first phase of the research revealed how wheelchairs and other forms of capital could either enable or curtail a resident's activities and mobility. These findings emphasize the critical role that institutional factors play in their lives in terms of physical layout and design, staffing levels, policies and procedures, and interactions with other residents and family. Based on these qualitative data, we identified potential variables for inclusion in the second phase of the study. The second phase of research identified predictors of mobility, participation, and life satisfaction among residents who use wheelchairs as their primary means of mobility. Wheelchair skills were the strongest predictors of mobility among proxy and self-responding subjects. Depression was the strongest predictor of participation for self-responding subjects and was the strongest predictor of life satisfaction for self-responding and proxy subjects.

Synthesis

Although the results from the qualitative and quantitative phases of the study were intended to be complementary (i.e., offering different perspectives on the topic of investigation), use of a mixed-methods research design invited comparing the findings from both phases of the study. Some findings prevailed across both phases of the study, but others were less consistent between the qualitative and quantitative phases.

Personal Factors

Physical ability was a personal factor that was important in both the qualitative and quantitative phases of the research. In the first, qualitative phase of the research, physical ability was an important form of capital and an enabler, in descending order of frequency, of mobility, participation, and life satisfaction. Similarly, in the second, quantitative phase of the research, physical ability, measured in terms of functional independence, was an independent predictor of mobility for the total sample and for proxy subjects, as well as an independent predictor of participation for the proxy subjects. It was not an independent predictor of life satisfaction. Most other personal factors were less consistent across both phases of the study.

In the qualitative phase of the study, pain was one of the least frequently identified barriers to mobility and participation but was the most commonly identified factor related to quality of life. A relationship between pain and quality of life has been posited (Kane, 2003; Stewart & King, 1994), which is logically appealing; however, this association was not supported by our findings in the second, quantitative phase of the study, as pain interference was

not correlated significantly with any of the outcomes. Although pain is very common among residents generally (Cadogan et al., 2008; Zanicchi et al., 2007), almost half of the residents indicated that pain did not interfere “at all” with their normal activities, so limited variation may have affected the statistical associations that were observed.

Income was an obvious and essential form of capital in the first phase of the research and it was frequently identified as an enabler of participation and to a lesser extent mobility and quality of life in chapter 3. In the second phase of the study, however, income was not significantly correlated with any of the outcomes. In terms of sampling, finances may have been more of an issue in the qualitative phase of the study for two of the younger residents who were on provincial disability assistance. We would have excluded these residents from the quantitative phase of the study because of the age-related inclusion criteria. Participants in the first phase of the study may also have used finances as a reason for not participating in activities they did not enjoy. In the second phase of the study, it may be that facility-related practices around mobility and participation may have lessened the effect of income on these outcomes for this larger, non-purposive sample, although there may be some issues associated with missing data for this measure.

As noted in chapter 3, in the qualitative phase of the study, depression was not associated with mobility and was the least frequently identified factor related to participation and life satisfaction. In the quantitative phase of the study, although decreased depression was not an independent predictor of mobility, it was moderately correlated with mobility for proxy subjects and the sample as whole. Depression was also the strongest independent predictor of life satisfaction for self-responding and proxy residents and of participation for self-responding residents. The discrepancy between the findings from the quantitative and qualitative phases of the study may reflect differences in the degree of depression in the samples from both phases of the research. For example, residents who were more depressed may have been less likely to take part in a longitudinal study versus a cross-sectional one, given the perceived participation commitment. It may also be explained by the fact that, in the first phase of research, we only coded negative statements of affect, because we considered positive statements about affect to represent the outcome of life satisfaction. In this regard, the relationship between happiness increased mobility, participation and quality of life was not explored. This inconsistency may also reflect a tendency among health professionals, including me as a qualitative researcher, to overlook symptoms of depression in this population, as older adults may underreport symptoms or present with somatic rather than affective symptomatology (Davison, et al., 2007; Teresi et al.,

2001). Furthermore, despite the prevalence of depressive symptoms in the current sample, this may represent an underestimation, as generic screening tools, like the GDS used in our study, are less sensitive in identifying depression in men (Oliffe & Phillips, 2008) and the GDS includes primarily affective depressive symptoms.

Cognition was a vital form of capital and was identified as a relatively common enabler of mobility and, less frequently, of participation and quality of life in the first phase of the study. In the quantitative phase of the study, Standardized Mini Mental Status Exam (SMMSE) (Molloy, 1999) scores were moderately correlated with mobility ($r=0.49$) for the total sample, but cognition was not an independent predictor of mobility for the total sample or for either subgroup. SMMSE scores were strongly intercorrelated ($r>0.65$) with Wheelchair Skills Scores and Functional Independence Scores, variables that had higher first order correlations with mobility, so it is not surprising that cognition did not add significantly to the variance explained. SMMSE scores was also moderately correlated with participation ($r=0.59$) for the sample as a whole but cognition was only an independent predictor of participation among proxy residents. For self-responding subjects, however, SMMSE scores were only weakly correlated with participation scores ($r=0.21$), possibly due to restricted variability in this measure for self-responding subjects, so it is not surprising that cognition among self-responding subjects was not an independent predictor of mobility for this subgroup. It may be that there is a cognitive threshold associated with participation, below which participation frequency declines; but at mild levels of cognitive impairment, the impact of cognition is outweighed by the effect of other variables.

Environmental Factors

The main environmental factors did not demonstrate consistent results across both phases of the research. In the first phase of the research, institutional factors were an important element of the themes we identified and we frequently recognized them as enablers of mobility, participation, and life satisfaction in chapter 3. In the second phase of the research, however, scores on the Craig Hospital Inventory of Environmental Factors (Whiteneck et al., 2004) revealed small but surprisingly positive significant correlations for the sample as a whole ($r=0.24$) with participation, which indicates that, as perceived barriers to participation increased, so did the frequency of participation. Furthermore, these perceived environmental barriers approached significance as a predictor of participation for self-responding subjects. These counter-intuitive findings might suggest that it is only through participation that residents become aware of barriers to participation in their environments. As many items were scored as

“0,” (the barrier is never encountered) with this environmental measure, it seems plausible that a floor effect was evident. This finding suggests this tool may not be very useful for assessing perceived environmental barriers among facility residents. Although we collected facility-level data, unconditional hierarchical linear models did not support the need for a linear mixed effects model of analysis. This result was unexpected, as it suggests that facility differences did not have an important influence on mobility, participation frequency, and life satisfaction outcomes for residents. However, these findings may also reflect the small number of facilities included in the research that would have increased the type II error rate, the non-random nature of the samples from each facility, and limitations of the measures used to capture these constructs. In this regard, we may not have adequately explored elements of the environment in the second phase of the study, given the study measures and design.

Social support was a key form of capital in the qualitative phase of the study. Assistance of friends and family was one of the most frequently identified enablers of participation and life satisfaction, but it was less frequently identified as an enabler of mobility. In the quantitative phase of the study, visits from friends and family were a significant predictor of mobility for proxy and self-responding subjects and for the sample as a whole; but visits were only fairly correlated with participation among proxy subjects. These findings are in contrast to a small number of other studies that have found that family involvement was associated with better quality of life (Gaugler, 2005). We simply measured the number of visits from friends and family, which is a crude measure of social support. It does not provide information about the quality of the interactions or support provided by telephone contact. Other measures of social support that tap into elements of social support such as tangible or emotional support might demonstrate stronger relationships with participation and life satisfaction, in particular, as the latter is a completely self-perceived construct.

Wheelchair-related Factors

Wheelchair skills were a central factor in both phases of the research. Wheelchair skills were one of the most frequently identified enablers of mobility in the qualitative phase of the study but were not associated with other outcomes. In the quantitative phase of the study, wheelchair skills were the single strongest independent predictor of mobility for the proxy and self-responding subjects and the sample as whole but were not an independent predictor of either participation or life satisfaction.

The influence of other wheelchair-related variables was less consistent across both phases of the study. In the first phase of the research, wheelchairs, which varied considerably across

participants, were vital forms of capital; and we identified wheelchair-related variables, like wheelchair appropriateness, as frequent enablers of mobility and less frequent enablers of mobility and life satisfaction in chapter 3. However, in the second phase of the research, as reported in chapter 4, wheelchair appropriateness, as measured using the Seating Identification Tool (SIT; Miller, Miller, Trenholm, Grant & Goodman, 2004) was not significantly correlated with mobility for the proxy, self-responding or combined samples. This finding is in contrast to previous research, using the same measure of wheelchair appropriateness, which found that SIT scores were the only significant predictors of mobility among a random sample of residential care residents from two of the facilities that were also included in the second phase of the current study (Bourbonniere, Fawcett, Miller, Garden & Mortenson, 2007). This result may reflect the characteristics of the convenience sample we obtained for our study or changes in these facilities over time. Wheelchair appropriateness may have been more closely associated with mobility if we had compared it to more continuous aspects of mobility, such as distance travelled or time spent wheeling. Wheelchair issues, which included several concerns related to restraints, were moderately correlated with mobility ($r=-0.45$) and participation ($r=-0.50$) for the sample as a whole and weakly correlated with satisfaction with life among proxy subjects ($r=-0.24$); however, it was not an independent predictor of any of these outcomes. There were three wheelchair variables that were independent predictors of study outcomes in the second phase of the research. These included 1) use of a power wheelchair as a predictor of mobility for the sample as a whole, 2) use of a seatbelt (not as a restraint) as a predictor of mobility for self-responding subjects, and 3) satisfaction with self-selected activities using a wheelchair as a predictor of life satisfaction for proxy subjects. As well, hours spent sitting in a wheelchair approached significance as a predictor of participation for self-responding residents. When considered together, the results from both phases of the research suggest that there is a relationship between wheelchair-related variables and mobility, but the relationship between wheelchair-related variables and participation and life satisfaction outcomes is less clear. This finding is not unexpected, given the increasing complexity of factors that shape residents' participation and their satisfaction with life. Furthermore, Diener and colleagues (1997) indicated that affective and personality factors are more likely to influence life satisfaction in comparison with more materialistic factors, such as income.

In summary, in considering the findings from both phases of the research together, there were a few consistent findings and larger number of mixed results, in which there was a lack of statistical support for the hypothesis generated through qualitative exploration. Physical ability

was a critical form of capital in the qualitative phase of the research and a significant predictor of mobility and to lesser extent participation in the quantitative phase of the research. Similarly, wheelchair skills were strongly associated with mobility in both phases of the study. Based on the qualitative phase of the research, stronger statistical associations between pain, social support, income, wheelchair factors and environmental factors, and study outcomes had been anticipated. Some of these mixed results may reflect 1) differences in the samples that participated in both phases of the research, as the first phase only included residents from two facilities and the second phase included nine additional facilities and had different inclusion criteria; 2) possible misunderstandings or misinterpretations in the qualitative phase of the research; and 3) measurement issues associated with some tools included in the second phase of the study. In contrast, depression was rarely identified as an enabler of mobility, participation, and life satisfaction in the qualitative phase of the study; yet it was one of the strongest independent predictors of life satisfaction and participation in the quantitative phase of the study. Finally, based on the qualitative phase of the research, wheelchair-related variables were anticipated to have stronger associations with the study outcomes. Some variables, like wheelchair appropriateness, were not significantly associated with study outcomes, whereas other variables, like wheelchair issues, were moderately correlated with some outcomes in bivariate analyses but were not independent predictors in our regression models. Finally, some variables, like use of a power wheelchair, use of a seatbelt, and satisfaction with wheelchair activities were independent predictors of some study outcomes but were not consistent across all study samples.

Personal Reflections

As an occupational therapist who has worked and researched in residential care for the last 10 years, it is interesting to reflect on the results of the study. Many of the findings resonate with clinical experiences I have had, especially given the longitudinal nature of data collection in the qualitative study. The impact of declining function on mobility and participation and the empowering effect of power wheelchair prescription are things that I have also observed in my clinical practice. As someone who has worked in these settings, to some extent I represented an “insider,” which may be beneficial in facilitating access and providing good background knowledge for the study. Being an “insider,” however, may discourage lines of inquiry that question taken-for-granted assumptions in these settings (Narayan, 1993). Despite my work as a clinician, my ethnographic observations as a researcher provided me with more vivid insights into the lives of residents living in the facilities. For example, I could share, to some extent, the

residents' frustrations when activities were cancelled where I had hoped to observe their participation. I also spent considerable time waiting with participants for various things and experienced somatic discomfort associated with sitting in the same position for prolonged periods. Although these short-term experiences are not the same as those of residents who have these experiences on a regular basis, they offered me a perspective that I did not fully comprehend as a clinician working in this area. The importance of family support and assistance was in keeping with my clinical experiences. I expected that frequency of visits would be an independent predictor of participation frequency and life satisfaction, but this lack of statistical association may have been due in part to our unsophisticated method of measuring this construct.

I was surprised by some of the findings of the quantitative phase of the study, which were counter to my clinical experiences. I expected institutional factors to be strongly associated with study outcomes, but the perception of physical and policy barriers was actually positively correlated with frequency of participation. If environmental barriers increased frequency of participation, this finding would contradict the results of other research in this area (Bland, 2007; Diamond, 1992; Kayser-Jones et al., 2003; Mortenson et al., 2005; Zimmerman et al., 2005), but it may also be an artifact of the method we used to measure these barriers and of our inability to examine facility level and personal level data simultaneously. I also expected factors such as wheelchair appropriateness to be associated with study outcomes, but this lack of association may reflect measurement and sampling issues.

It is interesting to consider the possibility of offering wheelchair skills training to residents in these facilities. As a clinician, I focused on such training only with power mobility users. For manual wheelchair users, I generally tried to ensure they were independently mobile on their wards. It seems logical that a client-centred approach to wheelchair skills training would focus on acquiring the skills residents want or need to have in order to participate in the occupations they desire. Such training would likely improve their mobility and might also facilitate their participation. It is also interesting to speculate on the potential of non-pharmacological interventions, such as participation in self-selected and valued occupations, to help alleviate symptoms of what could represent a reactive depression precipitated, in part, by facility admission (Ron, 2004).

Clinical Implications

The qualitative findings from this research are most relevant to the facilities involved in that phase of the research. These results suggest the need for alterations to policies and practices around restraint use, wheelchair provision (especially the use of wheelchairs that are not capable

of self-propulsion), and the need for changes in staffing. These findings may have applicability to other residential care facilities. As an exploratory, primarily descriptive study, this research offers a fairly low level of evidence for supporting practice change from an evidenced-based practice perspective (Greenhalgh, 1997). In the absence of higher levels of evidence, however, clinicians might take these findings into consideration and consider exploring the effect on mobility of residents of wheelchair skills training or provision of power wheelchairs.

To advocate for policy, practice, and funding changes, a social justice perspective may be useful. This viewpoint would help confront some of the aspects of residential facility life that are not as inevitable as they seem and pose questions such as: Why do some facilities only provide basic wheelchairs to residents? Why do some residents need to purchase wheelchairs that may only be appropriate for them for a limited amount of time (as their conditions change)? Would it be possible to create a regional equipment pool for residential care facilities so that facilities did not need to store equipment that they did not immediately need? Why are residents provided with wheelchairs that cannot be self-propelled, when similar wheelchairs that can be self-propelled are available at an equivalent cost? Why do residents on disability assistance receive such a small monthly allowance? Why is limited back-fill available for rehabilitation staff? Why do some residents need to wait for extended periods of time to receive the care they need? Why are facilities built that do not accommodate the need for equipment storage and wheelchair use? Most of the changes required to address these issues come at some financial cost, which always raises concerns about the need for fiscal restraint. Such concerns overlook the moral imperative we have to help look after those who have contributed to our society and continue to do so and to care for those who are the most vulnerable and in need. It also downplays the ways in which many who live outside of these institutions benefit from a society which has been largely created to accommodate autonomous individuals. Robertson (1997) has described this perspective as the moral economy of interdependence.

Strengths and Limitations of the Study as a Whole

The study as a whole had a variety of strengths and weaknesses. The use of a Bourdieusian lens was useful in the first phase of the study as a way of understanding the relationship between resident's personal agency and institutional structure. By facilitating an understanding of residents in a way that was not disability-specific, this approach helped to avoid conceptualizing residents as *other*, which is useful for facilitating change (Edwards & Imrie, 2003). The use of mixed-methods was a strength of the study. The initial qualitative phase of the research offered the opportunity to develop an in-depth understanding about the influence of the

wheelchairs on the lives of individuals in residential care and to identify novel variables that we did not find in a search of the existing literature, including cultural appropriateness of activities and wheelchair confidence. Drawing on multiple sources of data, the qualitative findings offered a means to contextualize and help explain the results of the quantitative phase of the research. The use of mixed-methods will also facilitate knowledge translation, in that the quantitative findings can be interrogated with qualitative data, and the quantitative findings can provide additional credibility to the qualitative findings. Some qualitative study limitations include the exclusion of non-English speaking residents and the relatively small number of study participants. As a method of identifying variables for inclusion in the second phase of the study, counting the frequency of codes embedded in the qualitative data was a limitation, as it did not provide an indication of the strength of the relationship between those coded examples and study outcomes. For example, a resident may have described several factors that facilitated mobility, but identified one that was most important. Some strengths of the quantitative phase of the study are inclusion of residents from 11 facilities and use of the Matching Person to Technology model (Scherer, 1998) to guide the research. Some quantitative limitations include the use primarily self-report measures, which raises issues of combining data from proxy and self-responding subjects. The use of proxy measures is also a limitation of the study, albeit necessary to allow us to use the same measure for both proxy and self-responding subjects. To deal with concerns about combining proxy and non-proxy data, we generally analyzed them separately, unless there was a compelling reason that allowed us to combine them. Although we attempted to obtain a random sample of residents, our primarily convenience sample limits the generalizability of the study findings. It should be pointed out that, in multivariate analyses generally, only the strongest predictors remain as independent predictors; but the results are dependent on the variables that were entered into the model. It is possible, with the inclusion of other variables, that different independent predictors would be identified. Finally, although we intended the research to identify predictors of study outcomes, the cross-sectional study design limits the ability of the study to determine causation. However, this study design was appropriate, given the exploratory nature of this research.

Future Work in this Area

The findings of this research may inform a variety of future qualitative and quantitative studies in this area and will lay the foundation for our ongoing program of research. From a geographic-gerontological perspective, additional research could explore how residents in other locales negotiate space and create a sense of place for themselves in these crowded facilities in

which activity is strictly regulated by institutional practices. Given the prevalence of residents who did not speak English, research that investigates the perceptions and experiences of these immigrant and non-English speaking individuals would be valuable. Future studies could also examine how families, friends, and volunteers facilitate the ongoing operation of these organizations. As a method of variable identification, the analyses of qualitative data seems to demonstrate some promise; but additional research could evaluate ways to improve the utility of this strategy, perhaps by using nominal groups or Delphi panel to decrease the time required.

Qualitative Research Questions

1. How do residents negotiate space and create a sense of place for themselves in residential care facilities?
2. How do the experiences of male residents differ from those of female residents?
3. What are the perceptions and experiences of facility life for residents from minority cultural groups?
4. What are the perceptions and experiences of facility life for residents who are non-English speaking?
5. What is the best way to sequence mixed methods studies? (i.e., How can qualitative research be best used to inform quantitative studies and vice versa?)

Given that much of the variance in mobility, participation, and life satisfaction scores remained unexplained, several descriptive, quantitative studies could be envisioned based on the findings of this research. Additional studies could eliminate measures that were not related to the study outcomes. Additionally, sense of control (Bowsher & Gerlach, 1990; Duncan-Myers & Huebner, 2000) and wheelchair self-efficacy, which were identified as potential constructs for measurement in chapter 3, could be included. Future studies could supplement self-report with measures that are more objective. For example, mobility could be measured by odometer readings or global positioning device tracking. Wheelchair skills and functional independence could be assessed by skill demonstration. Environmental barrier information could be collected by observational measures such as the one being developed by Cutler, Kane, Degenholtz, Miller, and Grant (2006). Furthermore, as model building is truly an exploratory approach, it bears repeating with different samples and different measures of those variables. Structural equation modeling would represent another analytic approach that would allow the relationship among multiple independent and dependent variables to be explored so that moderating and mediating variables that predict life satisfaction or participation could be identified.

Descriptive Quantitative Research Questions

1. What is the relationship between wheelchair-self efficacy, mobility, and participation?
2. What are the predictors of other aspects of mobility such as distance wheeled, time spent wheeling, bouts of wheeling, and places visited?
3. What effects do institutional factors (such as staffing levels, training, staff attitudes, quality of resident-staff communication, facility policies and practices, architectural features) have on the mobility, participation and life satisfaction of residents?
4. Does mobility act as a mediating variable between wheelchair related variables and participation and life satisfaction?

Development of new measures or refinement of existing ones is another potential avenue of future research. Although the Late Life Function and Disability Instrument- Disability Component was used as a measure of participation in this study, some items, such as preparing meals and overnight stays, were not applicable to many residents. In this regard, some dominant views of participation may not be relevant to individuals living in residential care settings. Based on the qualitative data from this study, it would be possible to construct a measure of participation that was more relevant for individuals living in residential care, which could be developed and tested. Modification made to the LLDI in the quantitative phase of the study would be a good place to start with the development of a new measure. It would also be helpful to capture participation in 1) some general types of facility organized indoor and outdoor activities [including a) passive activities such as attending performances, watching movies/ television; b) exercise groups; c) interactive groups such a baking, breakfast group or word games, and d) outings)]; 2) participation in self-generated activities inside the facility (such as visiting with other residents); and 3) participation in non-facility organized activities in the community (including attending church or going shopping). It would also be beneficial to supplement generic activities with self-nominated ones, such as smoking or pan-handling, so that participation in these less common occupations is not overlooked. This measure should include evaluations of participation frequency and subjective evaluations such as satisfaction with participation. Similarly, although we used the Craig Hospital Inventory of Environmental Factors (Whiteneck et al., 2004) as a measure of environmental barriers to participation, questions on this measure seemed difficult for residents to comprehend; and most items were scored as 0, which indicates a substantial floor effect. By creating a measure that was more residential facility specific and that used simpler sentence structure, a nursing home specific version of the measure could be envisioned.

Measurement Research Questions

1. Would a residential-care specific measure of participation among facility residents demonstrate better face validity and psychometric properties than current generic ones?
2. Would a residential-care specific measure of perceived environmental barriers demonstrate better face validity and psychometric properties than current generic ones?

Moving beyond description is important; because our depictions of problems are always retrospective, and, therefore, current reality can neither fully described nor understood. This study suggests the potential for a several intervention studies. An experiment could explore the impact of wheelchair skills training and provision of power mobility on residents in these settings. To increase participation and life satisfaction, interventions, including non-pharmacological ones that decrease depression, increase mobility, improve facility satisfaction, and facilitate satisfaction with wheelchair-related activity could be investigated via future intervention studies.

Intervention Study Research Questions

1. Does the provision of wheelchairs skills training or power mobility improve mobility among residents who use wheelchairs?
2. Does a program to increase participation in self-selected occupations decrease depression and improve participation satisfaction and life satisfaction among residents who use wheelchairs?

Personal Plans

As an essential part of this transformatory research, we are currently presenting the findings from both phases of the research back to the staff and residents at participating facilities as a form of knowledge translation. In the coming months, we will create a short video of the voices and images of residents using their wheelchairs in and around these settings that we will use to the study findings to other residential facility staff members and policy makers, We hope that this video will be useful to help advocate for better equipment and staffing levels in these facilities.

During my post-doctoral work, I will explore structural equation modeling as outlined above. Via my post-doctoral training, I will learn how to conduct a multi-site intervention trial. As I near the end of this training, I will begin to apply for research funding to enable me to carry out a multi-site trial that examines the impact of a wheelchair skills training program on resident's wheelchair skills, mobility and participation. Upon completion of my post-doctoral work, I hope to secure funding to enable me to carry out this research. Based on the findings of this research, additional knowledge translation and advocacy projects will be completed. With the potential of attracting graduate students of my own in the future, I would like to explore some of the other quantitative and qualitative questions that I have identified during my doctoral research.

Conclusion

This is one of the most comprehensive studies to date to examine the lives of residents who use wheelchairs as their primary means of mobility. In this mixed-methods project, we undertook an initial qualitative study to explore how residents and family members in residential care settings used wheelchairs and to develop an understanding of the context in which wheelchair use took place. Residents used wheelchairs as a method of mobility and as a method of providing comfort in sitting. Wheelchairs were used by staff to move and sometimes to restrain residents. Through the mobility they provided, wheelchairs enabled and sometimes curtailed resident access to certain spaces and participation in activities, which contributed to the residents' sense of place. Based on these qualitative data, we identified a variety of variables for inclusion in the second, quantitative phase of the study, which we used to identify predictors of mobility, participation, and life satisfaction among residents who use wheelchairs as their primary means of mobility. Wheelchair skills were the strongest independent predictor of mobility for the sample as a whole. For self-responding subjects, depression was the strongest independent predictor of participation and mobility approached significance. For self-responding and proxy subjects, depression was the strongest independent predictor of life satisfaction. For proxy subjects, mobility was the strongest independent predictor of participation; and depression approached significance. This exploratory research projects lays the foundation for a variety of future qualitative and quantitative studies including experimental studies that explore the efficacy of interventions aimed at improving the outcomes among residents.

References

- Bourbonniere M.C., Fawcett L.M., Miller, W.C., Garden J., & Mortenson W.B. (2007). Prevalence and predictors of need for seating intervention and mobility for persons in long-term care. *Canadian Journal on Aging, 26*, 195-204.
- Bland, M. (2007). Betwixt and between: A critical ethnography of comfort in New Zealand residential aged care. *Journal of Clinical Nursing, 16*, 937-944.
- Bowsher, J. E., & Gerlach, M. J. (1990). Personal control and other determinants of psychological well-being in nursing home elders. *Scholarly inquiry for nursing practice, 4*, 91-102; discussion 103-108.
- Cadogan, M.P., Edelen, M.O., Lorenz, K.A., Jones, M., Yosef, J., Hascall, T., Simon, B., Harker, J.O., Ferrell, B., & Saliba, D. (2008). The relationship of reported pain severity to perceived effect on function of nursing home residents. *Journal of Gerontology, 63A*, 969-973.
- Cutler, L.J., Kane, R.A., Degenholtz, H.B., Miller, M.J., & Grant, L. (2006). Assessing and comparing physical environments for nursing home residents: Using new tools for greater research specificity. *The Gerontologist, 46*, 42-51.
- Davison, T. E., McCabe, M. P., Mellor, D., Ski, C., George, K., & Moore, K. A. (2007). The prevalence and recognition of major depression among low-level aged care residents with and without cognitive impairment. *Aging and Mental Health, 11*, 82-88.
- Diamond, T. (1992). *Making gray gold: Narratives of nursing home care*. Chicago, IL: University of Chicago Press.
- Diener, E., Suh, E., & Oishi, S. (1997). Recent findings on subjective well-being. *Indian Journal of Clinical Psychology, 24*, 25-41.
- Duncan-Myers, A. M., & Huebner, R. A. (2000). Relationship between choice and quality of life among residents in long-term-care facilities. *The American Journal of Occupational Therapy, 54*, 504-508.
- Edwards, C., & Imrie, R. (2003). Disability and bodies as bearers of value. *Sociology, 37*, 239-256.
- Gaugler, J.E. (2005). Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health, 9*, 105-118.
- Greenhalgh, T. (1997). Assessing the methodological quality of published papers. *British Medical Journal, 315*, 305-308.
- Kane, R.A. (2003). Definition, measurement, and correlates of quality of life in nursing homes: Toward a reasonable practice, research, and policy agenda. *Gerontologist, 43*, 28-36.

Kayser-Jones, J., Schell, E., Lyons, W., Kris, A.E., Chan, J., & Beard, R.L. (2003). Factors that influence end-life care in nursing homes: The physical environment, inadequate staffing, and lack of supervision. *The Gerontologist*, *43*, 76-84.

Miller, W.C., Miller, F., Trenholm, K., Grant, D., & Goodman, K. (2004). Development and preliminary assessment of the measurement properties of the Seating Identification Tool (SIT). *Clinical Rehabilitation*, *18*, 317-25.

Molloy, D. W. (1999). *The Standardized Mini-Mental Status Exam (SMMSE)*. New Grange Press, Troy, Ontario, Canada.

Mortenson, W.B., Miller, W.C., Boily, J., Steele, B., Odell, L. Crawford, E.M. & Desharnais, G. (2005). Perceptions of power mobility use and safety within residential facilities. *Canadian Journal of Occupational Therapy*, *72*, 142-152.

Narayan, K. (1993). "How native is a 'native' anthropologist?" *American Anthropologist*, *95*, 671-685.

Oliffe, J.L., & Philips, M.J. (2008). Men, depression and masculinities: A review and recommendations. *Journal of Men's Health*, *5*, 194-202.

Robertson, A. (1997). Beyond apocalyptic demography. Toward a moral economy of interdependence. *Aging and Society*, *17*, 425-446.

Ron, P. (2004). Depression, hopelessness, and suicidal ideation among the elderly: a comparison between men and women living in nursing homes and in the community. *Journal of Gerontological Social Work*, *43*, 97-116.

Scherer, M.J. (1998). *The Matching Person and Technology (MPT) model and assignment instruments* (3rd ed.). Webster, NY: The institute for Matching Person & Technology.

Stewart, A. L., & King, A. C. (1994). Conceptualizing and measuring quality of life in older populations. In R. P. Abeles, H. C. Gift, & M. G. Ory (Eds.), *Aging and quality of life* (pp. 27–54). New York: Springer Publishing Company.

Teresi, J., Abrams, R., Holmes, D., Ramirez, M., & Elmicke, J. (2001). Prevalence of depression and depression recognition in nursing homes. *Social Psychiatry and Psychiatric Epidemiology*, *36*, 613-620.

Thomas, W. (1994). *The Eden alternative: Nature, hope and nursing homes*. New York: Eden Alternative Foundation.

Tinetti, M.E. & Ginter, S.F. (1990). The nursing home life-space diameter. A measure of extent and frequency of mobility among nursing home residents. *Journal of the American Geriatrics Society*, *38*, 1311-1315.

Whiteneck, G. G., Harrison-Felix, C. L., Mellick, D. C., Brooks, C. A., Charlifue, S. B., & Gerhart, K. A. (2004). Quantifying environmental factors: A measure of physical, attitudinal, service, productivity, and policy barriers. *Archives of Physical Medicine and Rehabilitation*, 85, 1324-1335.

Zanocchi, M., Maero, B. Nicola, E. Martinelli, E., Luppino, A., Gonella, M., Gariglio, F., Fissore, L. Bardelli, B., & Obialero, R. (2007) Chronic pain in a sample of nursing home residents: Prevalence, characteristics, influence on quality of life (QoL). *Archives of Gerontology and Geriatrics*, 47 , 121-128.

Zimmerman, S., Sloane, P.D., Williams, C.S., Reed, P.S., Preisser, J.S., Eckert, J.K., et al. (2005). Dementia care and quality of life in assisted living and nursing homes. *The Gerontologist*, 45, special issue 1, 133-146.

Appendix 1

Explication of Bourdieu's Concepts of Habitus, Field, and Capital

Habitus is defined as “an acquired system of generative schemes objectively adjusted to the particular conditions in which it is constituted, [...which] engenders all the thoughts, all the perceptions and all the actions consistent with those conditions and no others.” (Bourdieu, 1993a, p. 95) In this way habitus is a “mediating category” that seeks to bridge the rift between the binaries of subjectivity/objectivity, individual/society, homogeneity/diversity, freedom/necessity (Fuchs, 2003; Wacquant, 2004) or what Bourdieu describes as the “*dialectic of the internalization of externality and the externalization of internality*, or more simply, of incorporation and objectification” (Bourdieu, 1993a, italics in original, p. 72). For the purpose of this research, we tried to attend to the habits of thought and actions that participants exhibited, how these differed among participants, how these changed over time, how they were strategically employed by participants, and how the facilities tended to encourage some forms of habitus and discourage others.

Fields and Capital

Fields, or games (Bourdieu, 1984), represent “relatively autonomous social microcosms [which exhibit] their own distinctive structures and dynamics and functioning according to their own inner logics.” (p. 690) (Emirbayer & Williams, 2005) and are defined as “configuration [s] of objective relations between positions” (Bourdieu & Wacquant, 1992, p. 97). A complex society has a multitude of fields, some at the micro level (like families), some at the meso level (like institutions), and some at the macro level (like nations). There are academic fields (like law), economic fields, fields of cultural production (which includes the arts and sciences), and the field of power, which is Bourdieu's term for the society as a whole (Bourdieu, 1984). For this research, we tried to identify the various fields that residents encountered, including those inside and outside the facilities. In the facilities, we examined fields, which included resident's room, shared spaces, wards, and the facilities themselves. Outside the facilities, we considered the facility grounds, neighbourhood surrounding the facility, transportation vehicles, and public and private buildings that residents entered.

Each field has its own rules that specify which resources (forms of capital) are to be sought by agents within that field (Bourdieu, 1984). Bourdieu's conception of capital (which he equates with power) is not purely economic; however, and he describes how other immaterial forms of capital (cultural or symbolic) can be converted to power within fields at varying rates of conversion (Bourdieu, 1984). Within these fields, we tried to determine the types of capital

participants sought and how this capital was used as both a means and an ends. We tried to look at how capital was exchanged from one form to another. From this perspective, we tried to be sensitive to resource issues that influenced both residents and staff in these settings.

Habitus, Capital and Field

Habitus, capital, and field are interdependent and combine to produce individual and cultural practices which Bourdieu (1984) expresses with the formula: “[habitus] (capital)] + field = practice” (p. 101). Fields not only produce agents, imbued with particular dispositions (*habitus*), but they are also simultaneously constituted by them (Bourdieu, 1993b). Viewed synchronically, the state of any given field can be seen as a “balance sheet” (Bourdieu, 1984), which emphasises reproduction and the *status quo*. Viewed diachronically, however, the nature of the struggle of agents and classes within fields and their trajectories can be observed (Bourdieu, 1993) Rather than fostering complete revolution, contestants tend to be complicit in perpetuating the structure of fields as they rarely question the unspoken rules of the game (or *doxa*), which they have invested considerable resources to master (Bourdieu, 1984). Because of differential access to capital, however, competition in the field of power (among various social classes) tends to re-create existing power relations as it is an

integrative struggle and, by virtue of the initial handicap, a reproductive struggle, since those who enter this chase, in which they are beaten before they start, as the constancy of the gaps testifies, implicitly recognize the legitimacy of the goals pursued by those whom they pursue, by the mere fact of taking part. (Bourdieu, 1984, p. 165)

Bourdieu used the term “symbolic violence” to describe the social practices that “entice the dominated to contribute to their own domination by tacitly accepting, outside of any rational decision or decree of the will, the limits assigned to them.” (Bourdieu, 1998, p. 12) For this research, we tried to identify the unspoken rules and taken-for-granted assumptions about the nature of fields (*doxa*) and to identify instances in which acceptance of these rules and assumptions contributed to ongoing issues of oppression and social injustice (symbolic violence).

Habitus, Embodiment and Ease

Due to its relationship with capital, *habitus* represents the embodiment of class (Bourdieu, 1984). Via this process of embodiment

Strictly biological differences are underlined and symbolically accentuated by differences in bearing, differences in gesture, posture, and behaviour which express a whole relationship to the social world. (Bourdieu, 1984, p. 192).

Different experiences of embodiment are often the result of differences in social status (Bourdieu, 1984). While these alienated bodies are objectified in a manner similar to that described by feminist scholars (Bordo, 1989; Grosz, 1994), the bodies of the dominants, imbued with this sense of ease, in contradistinction are subjectified (Bourdieu, 1984). Differences in embodiment, based as they are on differences in class, are a particularly effective form of symbolic violence in that they promote a false, essentialist view of class membership that naturalizes differences. The idea of 'natural facility' represents what Bourdieu (1984) describes, in sesquipedalian style, as *allodoxia*, a false belief that tends to reinforce and reproduce *status quo*. In our research, we therefore tried to pay close attention to the manner in which ideas about age, ability, gender, race, and class influenced participant's self-perceptions, made differences attributable to these categorizations seem natural and discouraged interrogation of their social construction (Cruikshank, 2003; Oliver, 1984).

References

- Bordo, S. (1989). The body and the reproduction of femininity: A feminist appropriation of Foucault. In A. M. Jaggar, & S. R. Bordo (Eds.), *Gender/Body/Knowledge: Feminist reconstructions of being and knowing* (pp. 13-33) London: Rutgers University Press.
- Bourdieu, P. (2003). Participant objectivation. *The Journal of the Royal Anthropological Institute*, 9(2), 281-294.
- Bourdieu, P. (2000). Making the economic habitus: Algerian workers revisited. *Ethnography*, 1(1), 17-41.
- Bourdieu, P. (1993a). *Outline of a theory of practice* (R. Nice Trans.). New York: Cambridge University Press.
- Bourdieu, P. (1993b). *Sociology in question* (R. Nice Trans.). Thousand Oaks, CA: Sage.
- Bourdieu, P. (1984). *Distinction: A social critique of the judgement of taste*. Cambridge, MA: Harvard University Press.
- Bourdieu, P., & Wacquant, L. J. D. (1992). *An Invitation to Reflexive Sociology*. Chicago, IL: University of Chicago Press.
- Cruikshank, M. (2003). Learning to be old. Gender culture and ageing. Oxford, England: Rowman & Littlefield.
- Emirbayer, M., & Williams, E. M. (2005). Bourdieu and social work. *Social Service Review*, 79(4), 689.
- Fuchs, C. (2003). Some implications of Pierre Bourdieu's works for a theory of social self-organization. *European Journal of Social Theory*, 6(4), 387-408.
- Oliver, M. (1990). *The politics of disablement: A sociological approach*. London: St. Martin's Press.
- Wacquant, L. (2004). Following Pierre Bourdieu into the field. *Ethnography*, 5(4), 387-414.

Appendix 2
Ethical Approvals

Qualitative Phase Approval



The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road,
Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - FULL BOARD

PRINCIPAL INVESTIGATOR: William C. Miller	INSTITUTION / DEPARTMENT: UBC/Medicine, Faculty of/Rehabilitation Sciences/Occupational Therapy	UBC BREB NUMBER: H07-00900
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
Institution		Site
Vancouver Coastal Health (VCHRI/VCHA)		Vancouver Community
Providence Health Care		
Other locations where the research will be conducted:		
CO-INVESTIGATOR(S):		
John Oliffe		
Catherine L. Backman		
Ben Mortenson		
SPONSORING AGENCIES:		
N/A		
PROJECT TITLE:		

Wheelchair Use in Nursing Homes: An Exploratory Ethnographic Study

REB MEETING DATE: May 10, 2007		CERTIFICATE EXPIRY DATE: May 10, 2008	
DOCUMENTS INCLUDED IN THIS APPROVAL:		DATE APPROVED: June 12, 2007	
Document Name	Version	Date	
<u>Protocol:</u>			
Research proposal	2	May 22, 2007	
<u>Consent Forms:</u>			
Family member consent form (Appendix I)	3	May 25, 2007	
Resident consent (Appendix E)	2	May 22, 2007	
Staff / other Resident Consent form (Appendix J)	ver 2	May 25, 2007	
<u>Assent Forms:</u>			
Assent form for residents (appendix F)	2	May 22, 2007	
Assent form for other residents (appendix K)	2	May 22, 2007	
<u>Advertisements:</u>			
Pamphlet (Appendix B)	2	May 22, 2007	
Newsletter communication book posting (appendix A)	2	May 22, 2007	
<u>Questionnaire, Questionnaire Cover Letter, Tests:</u>			
Naturalistic and participant observations (appendix J)	N/A	April 16, 2007	
Interview Guide (appendix K)	N/A	April 16, 2007	
Demographic information (appendix L)	N/A	April 16, 2007	
<u>Letter of Initial Contact:</u>			
letter of initial contact for families (appendix D)	2	May 22, 2007	
Letter of initial contact for staff (appendix H)	N/A	May 22, 2007	
Letter of initial contact for other residents (appendix G)	1	May 22, 2007	
Letter of initial contact for residents (appendix C)	2	May 22, 2007	
<u>Other Documents:</u>			
Peer Review	N/A	April 16, 2007	

The application for ethical review and the document(s) listed above have been reviewed and the

procedures were found to be acceptable on ethical grounds for research involving human subjects.

*Approval is issued on behalf of the Behavioural Research Ethics Board
and signed electronically by one of the following:*

Ethical Approval for Quantitative Study



*The University of British Columbia
Office of Research Services
Clinical Research Ethics Board –
Room 210, 828 West 10th Avenue,
Vancouver, BC V5Z 1L8*

ETHICS CERTIFICATE OF FULL BOARD APPROVAL

PRINCIPAL INVESTIGATOR: William C. Miller	INSTITUTION / DEPARTMENT: UBC/Medicine, Faculty of/Occupational Science and Occupational Therapy	UBC CREB NUMBER: H08-00064
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
Institution		Site
Vancouver Coastal Health (VCHRI/VCHA)	Powell River/Sunshine Coast	
Vancouver Coastal Health (VCHRI/VCHA)	UBC Hospital	
Vancouver Coastal Health (VCHRI/VCHA)	North Shore Community (including Horseshoe Bay and up to Lions Bay)	
Vancouver Coastal Health (VCHRI/VCHA)	Richmond Health Services	
Vancouver Coastal Health (VCHRI/VCHA)	Sea to Sky Corridor (including Bella Bella,	
Vancouver Coastal Health (VCHRI/VCHA)	Bella Coola, Squamish, Whistler and	
Vancouver Coastal Health (VCHRI/VCHA)	Pemberton)	
Vancouver Coastal Health (VCHRI/VCHA)	Vancouver Community	
Providence Health Care		
Other locations where the research will be conducted:		
We want to include a random sample of facilities in the lower mainland, which may include the facilities/ sites above.		

<p>CO-INVESTIGATOR(S):</p> <p>John Oliffe Catherine L. Backman W. Ben Mortenson</p>
<p>SPONSORING AGENCIES:</p> <p>Canadian Institutes of Health Research (CIHR)</p>
<p>PROJECT TITLE:</p> <p>Wheeled Mobility of Nursing Home Residents</p>
<p>THE CURRENT UBC CREB APPROVAL FOR THIS STUDY EXPIRES: February 19, 2009</p>
<p>The full UBC Clinical Research Ethics Board has reviewed the above described research project, including associated documentation noted below, and finds the research project acceptable on ethical grounds for research involving human subjects and hereby grants approval.</p>

<p>REB FULL BOARD MEETING REVIEW DATE:</p> <p>February 19, 2008</p>																						
<p>DOCUMENTS INCLUDED IN THIS APPROVAL:</p> <table border="1"> <thead> <tr> <th>Document Name</th> <th>Version</th> <th>Date</th> </tr> </thead> <tbody> <tr> <td colspan="3"><u>Protocol:</u></td> </tr> <tr> <td>protocol</td> <td>2</td> <td>February 27, 2008</td> </tr> <tr> <td colspan="3"><u>Consent Forms:</u></td> </tr> <tr> <td>consent for residents</td> <td>2</td> <td>February 27, 2008</td> </tr> <tr> <td>consent form for surrogate decision makers</td> <td>2</td> <td>February 27, 2008</td> </tr> <tr> <td colspan="3"><u>Advertisements:</u></td> </tr> </tbody> </table>	Document Name	Version	Date	<u>Protocol:</u>			protocol	2	February 27, 2008	<u>Consent Forms:</u>			consent for residents	2	February 27, 2008	consent form for surrogate decision makers	2	February 27, 2008	<u>Advertisements:</u>			<p>DATE DOCUMENTS APPROVED:</p> <p>March 5, 2008</p>
Document Name	Version	Date																				
<u>Protocol:</u>																						
protocol	2	February 27, 2008																				
<u>Consent Forms:</u>																						
consent for residents	2	February 27, 2008																				
consent form for surrogate decision makers	2	February 27, 2008																				
<u>Advertisements:</u>																						

research notice	2	February 28, 2008
<u>Questionnaire, Questionnaire Cover Letter, Tests:</u>		
Wheelchair Skills Test	N/A	January 22, 2008
Snellen Eye Chart	1	February 27, 2008
Functional Independence Measure	N/A	January 22, 2008
Resident Satisfaction Questionnaire	N/A	January 22, 2008
Seating Intervention Tool	N/A	January 8, 2001
Craig Hospital Inventory of Environmental Factors	N/A	September 27, 2004
Demographic and additional questions	2	February 27, 2008
Comorbidity Index	N/A	January 22, 2008
Late life disability instrument	N/A	January 1, 2002
Vision and Hearing Minimum data set	1	February 27, 2008
Wheelchair Outcome Measure	1	June 1, 2004
GDS	N/A	January 1, 1986
Nursing Home Life Space Diameter	N/A	January 22, 2008
Satisfaction with Life Scale	2	February 27, 2008
Standardized Mini-mental status exam	N/A	January 1, 2005

Letter of Initial Contact:

Letter of initial contact (Residents)	2	February 27, 2008
Letter of initial contact (surrogate decision makers)	2	February 27, 2008

CERTIFICATION:

In respect of clinical trials:

- 1. The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Division 5 of the Food and Drug Regulations.*
- 2. The Research Ethics Board carries out its functions in a manner consistent with Good Clinical Practices.*
- 3. This Research Ethics Board has reviewed and approved the clinical trial protocol and informed consent form for the trial which is to be conducted by the qualified investigator named above at the specified clinical trial site. This approval and the views of this Research Ethics Board have been documented in writing.*

The documentation included for the above-named project has been reviewed by the UBC CREB, and the research study, as presented in the documentation, was found to be acceptable on ethical grounds for research involving human subjects and was approved by the UBC CREB.

Appendix 3

Participant Observation and Interview Guide Examples

Participant Observation Guides Examples

1. How do residents use their wheelchairs/

Who self-propels?

Who does not?

What are some factors associated with the ability to propel versus not propel? (type of wheelchair, method of propulsion (arms, feet, powered) etc.)

Who can self-apply the brakes?

Who can self-disengage the brakes?

2. What do residents do with their wheelchairs?*

3. Where do residents go with their wheelchairs?*

4. How long do they stay at the places they go?*

5. How do staff and others interact with residents?*

What kind of assistance do they provide?

How do they communicate with residents in wheelchairs?

6. How do residents interact with one another?*

7. What kind of temporal and spatial variation in wheelchair use exists within and between residents?

8. How do family members use wheelchairs in these settings?

9. What kind of barriers and facilitators to mobility and participation do residents encounter?*

* and how is this different for individuals who self propel versus those who can not?

Interview Guide

Residents (or family member surrogates):

1. Typical Day

Tell me what an average day is like for you (and your____)?

2. Mobility

How do you (does your____) get from place to place?

What kind of things does the wheelchair help you (him/her) do?

How well are you (is he/she) able to move your (his/her) wheelchair? (in the facility, outside the facility, other locations)

What kinds of things are hard to do with it?

What things does your (his/her) wheelchair prevent you (him/her) from doing?

Have you (has he/she) ever had an accident in your (his/her) wheelchair?

3. Access

What kind of assistance do you (does he/she) get with your (his/her) wheelchair? (getting in and out, helping you move around, taking you places, who helps you with what?)

How did you (he/she) get the wheelchair you have (she/he has) currently (funding, prescription)?

What was the process like for you (and for him/her)?

How do you maintain your wheelchair? (How is the wheelchair maintained?)

4. Participation

What kind of things do you (does he/she) do?

Are you (Is he/she) able to take part in all the activities you want (he/she wants) to?

What would make it easier for you (him/her) to participate?

5. Attitudes/Experiences

What do you think about your (the) wheelchair? (comfort, aesthetics, generally)

How do people treat you (him/her) when you are (he/she is) using your (the) wheelchair?

How does the wheelchair make you (him/her) feel?

What impact did getting a wheelchair have for you (and him/her)?

6. Perceptions about the facility

How would you describe your regular interactions with the staff?

When do you see them? How often?

Who tends to initiate interactions with staff

Do some residents get better treatment than others?

7. Quality of life

How happy are you with the level of privacy you have here?

How much control do you (does you relative) have over your (his/her) day?

How is it (for him/her) living with/without roommates?

What's it like to rely on staff for help?

8. Catching up (for second and third interviews only)

How have things been since we last spoke?

Has anything changed since we last talked?

... with you, with your WC, or with the facility?

Following up with specific questions from previous interviews

9. Changes

What kind of changes would you like to see at the facility?

Staff:

1. Work experiences with wheelchairs

What have been your experiences with the wheelchair?

What role do wheelchairs play in a typical day for you?

How are wheelchairs maintained?

2. Role of wheelchair duties in this setting including policies and procedures?

What kind of assistance do you provide to residents with their wheelchairs? (getting in and out, helping move, taking them places)

What wheelchair related duties do you have?

What are the policies or procedures that you follow with wheelchairs?

3. Staff observations of resident wheelchair use

What kind of things do wheelchairs help residents do?

What kind of difficulties do residents encounter with their wheelchairs?

What do wheelchairs assist residents to do?

What kinds of things do wheelchairs prevent residents from doing?

What have you noticed about the use of wheelchairs as restraints? (With brakes applied so that resident can't move, residents in wheelchairs that can not be self-propelled, or wanderguard systems, for example)

What experience do you have with residents being restrained in wheelchairs?

What about transfer slings being left under residents?

3. Attitudes

What are your personal thoughts about wheelchair?

When is a wheelchair most useful?

4. Facility Resources

What kind of activities are residents involved in?

On what basis are things provided to residents (assistance, equipment, bus outings, garden plots) etc.?

How do you deal with multiple demands?

5. Additional questions for wheelchair prescribers about the prescription process?

How do you prescribe wheelchairs to residents living in the facility?

How do residents get the wheelchairs that they have?

6. Changes

What kind of changes would you like to see happen at the facility?

Appendix 4

Member Checking Process

We presented residents and family members with a summary of the findings from the preliminary analysis of the qualitative phase of the data during their final interviews. We provided staff members the same summary as part of their individual interviews. To decrease the demands on participants and time required, we combined the Bourdieusian and variable selection analyses by focusing on important commonalities in each. During this process, we described four preliminary themes (as detailed below) and reviewed a conceptual diagram (see figure indicating the relationship between mobility, participation, quality of life, and environmental factors (see below)). When talking with residents, we provided specific examples pertaining to each participant to illustrate how they fit within the themes and conceptual model. We asked participants to comment on how the themes and the conceptual model resonated with them; and we followed up these comments with additional questions. We transcribed and coded these member-checking interviews [excluding investigator presentations of the themes and conceptual model], so that they become part of the data, which informed the final analyses presented in chapters 2 and 3.

Summary of Themes

1. Needing/depending

- residents admitted because of physical and cognitive impairments, which prevented them from caring for themselves in the community
- they need help with certain activities, but this makes them dependent on wheelchairs for mobility and staff for assistance

2. Constricting time and space (includes restraining)

- residents restricted in terms of where and when they go
- residents with dementia confined to floor with Wanderguard system,
- some residents restrained in their wheelchairs (tilt in space or Brodas that residents cannot self-propel),
- process of admission (going from apartment or home to 1-4 bed room) (downsizing),
- lifestyle altered to fit into the facility scheduling (showers once a week, meal times)

3. Restricting participation

- programming tends to be group focused and mostly English based
- limited evening and weekends programming, biomedical takes precedent (flu outbreaks etc.),

- limited vacation and sick coverage of rehabilitation staff
4. Acting.

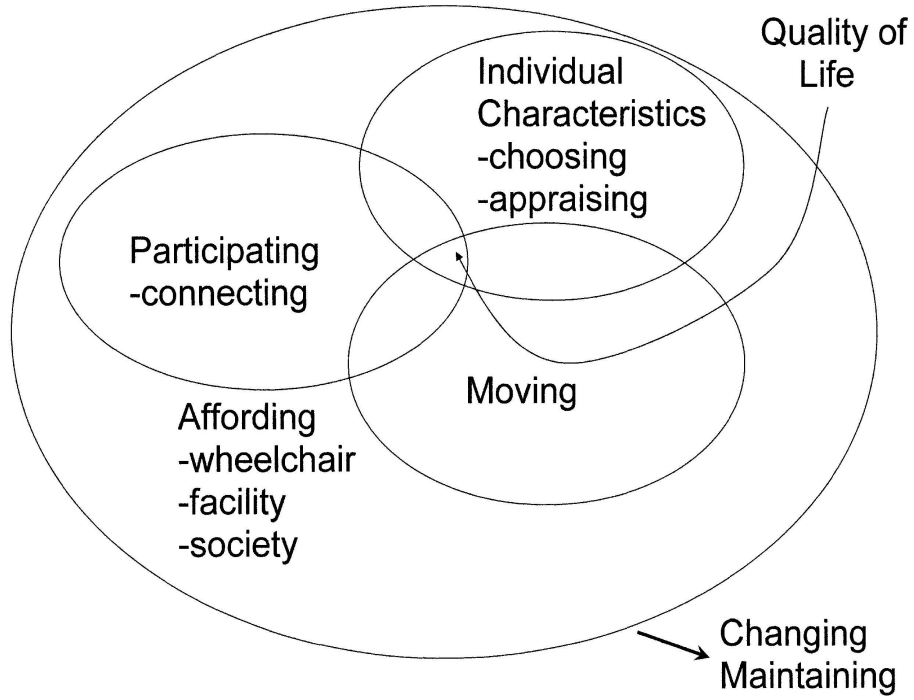
- Residents frequently are not passive care recipients.
- They do things to assert their own autonomy.
- They try to give back (altruism), etc.; giving, not just receiving, care.
- Resisting care at times, as well.

Description of Quality of Life Model for Participants

Quality of life is the result of an interaction between an individual participating, moving (in the wheelchair, but also their bodies in space) and individual characteristics (including subjective appraisals). All of these things occur within an environmental context, which either helps or hinders these things [at the level of the wheelchair, the facility (policies, practices and physical layout), and society (policies and accessibility outside the facility)]. These are not static processes and occur over time, over changing life courses in which participating, moving and thinking either remain the same or change (either increasing or decreasing). For example, getting a new power wheelchair (because the resident can afford to pay the whole cost), may increase mobility (moving) and participating. In contrast, someone with increasing problems as the result of multiple sclerosis might lose the ability to move, think, and participate, but because they adjusted how they viewed quality of life and still maintain a positive outlook.

Figure A4.1

Conceptual Diagram of Quality of Life for Residents



Appendix 5

Rationale for Tool Selection

Finding appropriate tools to measure these factors and variables represents a potential challenge. When selecting possible measures we considered a number of elements including psychometric properties, intended population (especially in terms of self-responding residents versus those with dementia), subjective or objective evaluation, utility, and specific content. Focusing on the latter criteria, we developed a list of potential measures, which we organized according to the factors and variables identified in the preliminary qualitative phase of the research, that we present in the following table. For some factors like cognition, pain and participation a number of potential measures exist. For some factors like the assistance of family and friends, as distinct from psychological support and cultural appropriateness we were unable to identify any standardized measures. This indicates the opportunity to develop new instruments or modify existing ones measures to capture these variables.

Table A5.1: Possible Tools to Measures Factors and Variables Identified in the Qualitative Phase of the Research

Variables	Potential Measures (selected measure(s) bolded)	Rationale for selection
Assistance of Family and friends	<ul style="list-style-type: none"> Perceived Social Support Scales (Procidano & Heller, 1983). Frequency of visits 	Measures of social support exist, but tend to focus on perceived psychological support like the Perceived Social Support Scales (Procidano & Heller, 1983). As a surrogate measure of assistance, we measured frequency of visits, which is a common way to measure the involvement of family and friends in residential care (Port et al., 2003)
Cognition (problem solving, memory, visual perceptual, route finding)	<ul style="list-style-type: none"> Mini mental state exam (Folstein, Folstein & McHugh, 1975) Modified mini mental status exam (3MS) (Jones et al., 2002) Trail Making Trail making A&B (Reitan & Wolfson, 1985) 	A standardized version of the mini-mental status exam was used for this study to increase the reliability of administration of the measure. This measure is commonly used in residential care facility research and would allow comparison of results with other studies.
Communication	<ul style="list-style-type: none"> Functional Independence Measure (FIM, Keith et al., 1987) (questions 14, 15) 	The FIM is a commonly used measure of functional ability and its use would facilitate comparisons with other studies.
Control	<ul style="list-style-type: none"> Duncan Choice Index (Duncan-Meyers & Huebner, 2008) Nursing Home Quality of Life Scales (NHQOLs) have 4 autonomy Qs (Kane et al., 2003) 	As this variable was only associated with life satisfaction in the first phase of the study, we elected not to measure it in the quantitative phase of the study to reduce respondent burden.

Variables	Potential Measures (selected measure(s) bolded)	Rationale for selection
Cultural appropriateness	<ul style="list-style-type: none"> Unable to locate 	Facility satisfaction questionnaires like the Resident Satisfaction Questionnaire (Chou, Boldy, Lee, 2002), ask about satisfaction with facility related activities, which is likely related to cultural appropriateness of activities. We also recorded country of birth to see if there were differences between residents from primarily Caucasian, English speaking countries and residents from other countries, but as the study excluded non-English speakers, these differences may have been obscured.
Depression	<ul style="list-style-type: none"> Geriatric Depression Scale (GDS; Brown & Schinka, 2005(Proxy version); D'Ath, Katona, Mullan, & Evans, 1994) Centre for Epidemiological Studies Depression Scale (Herzog et al., 1990) 	The GDS was selected as psychometric testing had been done on a proxy version of this measure and it was commonly used in residential care facility research.
Finances	<ul style="list-style-type: none"> Income Two study specific questions on the impact of finances on resident's wheelchair received and participation were also administered. 	As missing data is often a problem with measures of income, we collected data on resident's daily room rate, which is based on their annual income after taxes.
Health	<ul style="list-style-type: none"> General health question 1 SF-12 (Jenkinson et al., 1997) 	To obtain a subjective rating of self-perceived health, the well-validated and commonly used general health

Variables	Potential Measures (selected measure(s) bolded)	Rationale for selection
	<ul style="list-style-type: none"> • Functional Comorbidity index (Groll, To, Bombardier & Wright, 2005) 	question from the SF-12 was used. To supplement this with more objective data the comorbidity index was used, which identifies general health related conditions that have functional implications.
Institutional Factors (crowding, hallway clutter, availability of equipment, staffing, recreational programming, training)	<ul style="list-style-type: none"> • CHIEF (Whiteneck et al, 2004) • MQE (Boschen, Noreau, Fougeryrollas, 1998) • Nursing Home Environmental Assessment (Cutler, Kane, Degenholtz, Miller & Grant, 2006). 	The MQE includes 109 items covering 23 domains, which makes it long for respondents and problematic for researchers. The Nursing Home Environmental Assessment is still under development and was not available from the authors when contacted. The CHIEF was, therefore, selected in light of its brevity and conceptual coverage.
Natural Environment (hills, rain, snow)	<ul style="list-style-type: none"> • CHIEF (question 5) • RSQ (question 6) 	See above
Mobility	<ul style="list-style-type: none"> • Nursing Home Life Space Diameter Measure (NHSLSD; Tinetti & Ginter, 2001) 	The NHLSD was used as a measure of mobility as it captures mobility performance rather than capacity and has been used in previous research with this population, which would facilitate comparisons (Bourbonniere et al., 2007).
Pain	<ul style="list-style-type: none"> • Pain severity (11 point scale from Minimum Data Set (MDS)) • Pain interference (question 9 from SF-12; 	We explored the instruments suggested by Stolee et al. (2005) in their review of pain assessment instruments for individuals with cognitive impairment, but the Pain

Variables	Potential Measures (selected measure(s) bolded)	Rationale for selection
	Jenkinson et al., 1997). <ul style="list-style-type: none"> • Pain Behaviour Measure (Keefe & Block, 1982) 	Behaviour Measure (Keefe & Block, 1982), which was one of the better rated tools, required video taping, which would have increased respondent burden. We used single item pain severity and pain interference questions therefore because of their brevity and conceptual coverage.
Participation	<ul style="list-style-type: none"> • Late-Life Function and Disability Instrument-Disability Component (LLDI; Jette et al., 2004) • Life-H (Noreau et al., 2004) • Impact of Participation on Autonomy (IPA; Cardol et al., 2004) • WhOM (Mortenson, Miller & Miller-Polgar, 2007) 	The LLDI was selected because it was a brief measure that captured frequency of participation in activities that were not exclusively limited to facility based activity programs. The Life-H was not selected because it penalizes participants who use assistive technology and the IPA was not used as it measures the effect of participation on autonomy rather than participation itself. LLDI data was supplemented with WhOM information to capture satisfaction with performance of activities while using a wheelchair.
Physical Ability (ability to move wheelchair, transfers, vision, hearing, health)	<ul style="list-style-type: none"> • Physical Function <ul style="list-style-type: none"> ○ FIM (Keith et al., 1987) ○ Modified Barthel Index (Shah, Vanclay & Cooper, 1989) ○ Katz index (Katz et al., 1970) 	There are a large number of measures of function available. Most wheelchair user specific ones have limited psychometric testing, (Mortenson, Miller, and Auger, 2008). The FIM was selected given its psychometric properties and frequency of use. As

Variables	Potential Measures (selected measure(s) bolded)	Rationale for selection
	<ul style="list-style-type: none"> • Hearing <ul style="list-style-type: none"> ○ Audiology ○ MDS vision item • Vision <ul style="list-style-type: none"> ○ Snellen eye test ○ MDS vision item 	<p>respondent burden precluded the collection of audiology data, the single hearing item from the MDS was used. The Snellen eye test was administered to subjects, but given concerns about potential missing data, this was supplemented with the vision item from the MDS</p>
Satisfaction with other residents	<ul style="list-style-type: none"> • RSQ includes one item: “opportunities to socialize with other residents.” • NHQOLS (Kane et al, 2003) has one scale on relationships) 	<p>As satisfaction with other residents was already covered in the RSQ it was elected not to add additional items from the NHQOLS which would have added to the respondent burden</p>
Satisfaction with/without room mates	<ul style="list-style-type: none"> • Number of room mates • NHQOLS (Kane et al, 2003) has one scale on relationships) 	<p>We recorded number of room-mates to determine if having a room mate was related to the study outcomes.</p>
Satisfaction with Life	<ul style="list-style-type: none"> • Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985). • NF-QOLS (Kane et al, 2003) 	<p>The SWLS was selected as it provided a global assessment of quality of life that could easily be used in statistical analysis. The NF-QOLS included 54 items from 11 domains that were intended to supplement information obtained from the Minimum Data Set. Given the respondent burden and lack of a total score for this measure, it was not selected for inclusion in the study.</p>

Variables	Potential Measures (selected measure(s) bolded)	Rationale for selection
Societal Factors (discrimination, funding, transportation, assistance from public)	<ul style="list-style-type: none"> • CHIEF Q1= transportation, discrimination = Q21, Q 23 &25 • MQE 	As noted above, given utility issues associated the MQE, the CHIEF was selected to measure environmental factors.
Wheelchair appropriateness (comfort, set up for independent propulsion, positioning in chair)	<ul style="list-style-type: none"> • Seating Identification Tool (SIT; Miller, Miller, Trenholm, Grant & Goodman) • TAWC (formerly WCS-DAT) (Crane et al., 2004) • Wheelchair issues 	A measure of wheelchair seating discomfort exists (Crane et al., 2004), but was deemed too lengthy for inclusion in the study, especially given that this construct was also covered in the more general SIT (Miller et al., 2004). SIT information was supplemented with a study specific-measure we created entitled “wheelchair issues” which included primarily restraint related issues we identified in the qualitative phase of the research.
Wheelchair confidence	<ul style="list-style-type: none"> • No standardized measure available 	Hoening et al. (2005) used a study specific measure of wheelchair confidence in their experimental study, but this was not subjected to any psychometric testing. In the absence of this testing and limited frequency of coding of this item in the qualitative phase of the study we elected not to collect information on this variable to decrease respondent burden.

Variables	Potential Measures (selected measure(s) bolded)	Rationale for selection
Wheelchair skills	<ul style="list-style-type: none"> <li data-bbox="443 298 1161 386">• Wheelchair Skills Test (WST; Mountain, Kirby & Smith, 2004) <li data-bbox="443 412 1161 500">• Wheelchair Obstacle Course (Routhier, Desrosiers, Vincent, & Nadeau, 2005) 	<p data-bbox="1192 298 1902 602">The WST was selected as this was the most comprehensive measure of wheelchair skills, it has alternative forms for power and manual wheelchair users and had good psychometric testing results for a questionnaire version of the measure (Mountain, Kirby, & Smith, 2004).</p>

References

- Boschen K, Noreau L, Fougere P. (1998). A new instrument to measure the quality of environment for persons with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 79, 1331.
- Cardol, M., de Haan R. J, van den Bos, G. A. M., de Jong, B. A., & de Groot, I. J. M. (1999). The development of a handicap assessment questionnaire: The Impact on Participation and Autonomy (IPA). *Clinical Rehabilitation*, 13, 411–419.
- Crane, B.A, Holm, M.B., Hobson, D., Cooper, R.A, Reed, M.P., & Stadelmeier, S. (2004). Development of a consumer-driven Wheelchair Seating Discomfort Assessment Tool (WcS-DAT). *International Journal of Rehabilitation Research*, 27, 85-90.
- Cutler, L.J., Kane, R.A., Degenholtz, H.B., Miller, M.J., & Grant, L. (2006). Assessing and comparing physical environments for nursing home residents: Using new tools for greater research specificity. *The Gerontologist*, 46, 42-51.
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment*, 49, 71-75.
- Hertzog, C., Van Alstine, J. Usala, P. D., Hultsch, D. F., Dixon, R. (1990). Measurement properties of the center for epidemiological studies depression scale (CES–D) in older populations. *Psychological assessment*, 2, 64-72.
- Hoening, H., Landerman, L.R., Shipp, K.M., Pieper, C., Pieper, C., Richardson, M., Pahel, N., & George, L. (2005). A clinical trial of rehabilitation expert clinician versus usual care for providing manual wheelchairs. *Journal of the American Geriatric Society*, 53, 1712-1720.
- Jones, T.G., Schinka, J.A., Vanderploeg, R.D., Small, B.J., Graves, A.B., Mortimer, J.A. (2002). 3MS normative data for the elderly, 17, 171-177.
- Kane, R.A., Kling, K.C., Bershadsky, B., Kane, R.L., Giles, K., Degenholtz, H.B., Liu, J. & Cutler, L.J. (2003). Quality of life measures for nursing home residents. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 58, 240-248.
- Katz S., Down, TD, Cash, H.R et al. (1970). Progress in the development of the index of ADL. *Gerontologist*, 10, 20-30.
- Keefe, F.J. & Block, A.R. (1982). Developing an observation method for assessing pain behaviour in chronic low back pain patients. *Behaviour Therapy*, 13, 363-375.
- Keith R.A., Granger, C.V., Hamilton, B.B., & Sherwin, F.S. (1987). The functional independence measure: A new tool for rehabilitation. *Advances in Clinical Rehabilitation*, 1, 6-18.

Miller, W.C., Miller, F., Trenholm, K., Grant, D., & Goodman, K. (2004). Development and preliminary assessment of the measurement properties of the Seating Identification Tool (SIT). *Clinical Rehabilitation, 18*, 317-25.

Molloy, D. W. (1999). *The Standardized Mini-Mental Status Exam (SMMSE)*. New Grange Press, Troy, Ontario, Canada.

Mortenson, W.B., Miller, W.C., & Auger, C. (2008). Issues for the Selection of Wheelchair-Specific Activity and Participation Outcome Measures: A Review. *Archives of Physical Medicine and Rehabilitation, 89*, 1177-1186.

Mortenson W.B., Miller W.C., & Miller-Polgar J. (2007). Measuring wheelchair intervention outcomes: Development of the wheelchair outcome measure. *Disability and Rehabilitation. Assistive Technology, 2*, 275 - 285.

Mountain, A.D., Kirby, R.L., & Smith, C. (2004). The wheelchair skills test, version 2.4: Validity of an algorithm-based questionnaire version. *Archives of Physical Medicine and Rehabilitation, 85*, 416-423.

Noreau, L., Desrosiers, J., Robichaud, L., Fougereyrollas, P., Rochette, A., & Viscogliosi, C. (2004). Measuring social participation: reliability of the LIFE-H in older adults with disabilities. *Disability and Rehabilitation, 26*, 346–352.

Port, C.L., Hebel, J.R., Gruber-Baldini, A.L., Baumgarten, M., Burton, L. et al. (2003). Measuring the frequency of contact between nursing home residents and their family and friends. *Nursing Research, 53*, 52-56.

Procidano M.E., Heller, K. (1983). Measures of perceived social support from friends and from family: three validation studies. *American Journal of Community Psychology, 11*, 1–24.

Reitan, R.M., & Wolfson, D. (1985). *Manual for administration of neuropsychological test batteries for adults and children*. Tucson, AZ: Neuropsychological Press.

Routhier, F., Desrosiers, J., Vincent, C., & Nadeau, S. (2005). Reliability and construct validity studies of an obstacle course assessment of wheelchair user performance. *International Journal Rehabilitation Research, 28*, 49-56.

Shah, S., Vanclay, F., & Cooper, B. (1989). Improving the sensitivity of the Barthel Index for stroke rehabilitation. *Journal of Clinical Epidemiology, 42*, 703-709

Stolee, P., Hillier, L.M., Esbaugh, J., Bol, N., McKellar, L., Gauthier, N. (2005). Instruments for the assessment of pain in older persons with cognitive impairment. *Journal of the American Geriatric Society, 53*, 319-326

Appendix 6

Description of Measures and Their Coding

The following table provides the 1) name of each measure, 2) construct it measures, 3) domains it covers, 4) number of items it has, 5) nature of data, 6) how it was coded, and psychometric property references. After the table a copy of each measure, as permitted by copyright restrictions are provided.

Table A6.1: Description of Measures Included in the Study and their Coding

Name of Measure	Construct	Items and Domains	Coding Continuous or discrete (range), coding	Reliability/ Validity Data
<hr/>				
Personal Factors				
Comorbidity Index	Comorbidity	18 dichotomous items (diagnoses) from one domain	Continuous (0-18), 0=no, 1= yes	Groll, To, Bombardier & Wright (2005)

Name of Measure	Construct	Items and Domains	Coding Continuous or discrete (range), coding	Reliability/ Validity Data
Demographic Information	Medical-Demographic Factors	1. Age (integer) 2. Sex. 3. Country of birth. 4. Length of stay 5. Number of room mates 6. Diagnoses (not included in CMI) 7. Number of medications (excluding vitamins and PRNs) 8. Number of cigarettes smoked in last week 9. Veteran 10. Daily rate	1. Continuous (0+) 2. Discrete (0 = female 1= male) 3. Discrete, text (+English speaking countries coded as 0 (USA, Canada, Ireland, England, Wales, Australia) other countries coded as 1) 4. Continuous (1+), months 5. Discrete (0+) 6. Discrete (text) 7. Continuous (0+) 8. Continuous (0+) Coded discretely as 0=0, >0=1 9. Discrete (0=no, 1=yes) 10. Continuous (0+)	--

Name of Measure	Construct	Items and Domains	Coding Continuous or discrete (range), coding	Reliability/ Validity Data
Functional Independence Measure	Functional Ability	17 (7-point response scale) items from 6 domains: self-care, sphincter, transfers(tub transfer item omitted), locomotion, communication and social cognition	Continuous (17-119) 7=complete independence, 6=modified independence (device), 5= supervision, 4= minimal assistance(A), 3= moderate A, 2=maximal A, 1=total A	Keith, Granger, Hamilton, & Sherwin, (1987)
General Health	Health	1 item in one domain with 5-point response scale	Discrete (0-4) 0=poor, 4= excellent	Jenkinson et al., (1997)
Geriatric Depression Scale	Depression	15 items in one domain, question 9 modified (home replaced with nursing home)	Continuous (0-15) 0= no, 1=yes (except for items that are reversed scored)	D'Ath, Katona, Mullan, & Evans (1994) Brown & Schinka (2005) (Proxy version)
Hearing (MDS (2.0))	Hearing	1 item with a 4 point response scale	Discrete (0-3) 0=hears adequately, 3=highly impaired	--
Pain Interference Question SF-12	Pain	1 item in one domain with 5-point response scale	Discrete (0-4) 0=not at all, 4= extremely	Jenkinson et al., (1997)

Name of Measure	Construct	Items and Domains	Coding Continuous or discrete (range), coding	Reliability/ Validity Data
Room rate	Finances	1 item: Daily room mate based on an 11-category response scale	Discrete (29.90-71.80)	--
Standardized Mini-Mental State Exam	Cognition	22 items in 5 domains: orientation, registration, attention and calculation, recall and language	Continuous (0-30, adjusted for items that were not applicable)	Molloy (1999)
Vision	Vision	1 item 5 point response scale item	Discrete (0-4) 0=adequate, 4= severely impaired	--
Wheelchair Factors				
Additional wheelchair related factors	Wheelchair specifications	1. length of time using a wheelchair 2. hours per day sitting a wheelchairs 3. presence of a seat belt 4. wheelchair description (make/model) 5. footrests 6. type of wheelchair	1. continuous (0+) months 2. continuous (0+) hours 3. discrete (0=no, 1=yes) 4. text 5. discrete (0 = none, 1= standard 2= elevating) 6. 1= manual chair with foot rests; 2= recliner wheelchair; 3= wheelchair without footrests (feet on floor); 4= wheelchair with one foot rest (other foot on floor); 5=Tilt in space wheelchair	--

Name of Measure	Construct	Items and Domains	Coding Continuous or discrete (range), coding	Reliability/ Validity Data
Seating Identification Tool	Need for wheelchair/ seating intervention	7. more than one wheelchair 8. cushion text and type 9. back 10. base 11. head rest 12. resident owns their own wheelchair 11 dichotomous items in one domain	that could potentially be self-propelled; 6= power wheelchair without tilt; 7= power wheelchair with tilt; 8= scooter; 9= wheelchair that cannot be self-propelled (6-8= power wheelchair); 10= tilt-in space +recline 7. discrete (0=no, 1=yes) 8. discrete (text) +0= no cushion; 1=Gel cushion; 2=Air cushion; 3=Foam cushion; 4=Hybrid cushion (combo of gel or air and foam) 9. discrete (sling = 0 personal back =1) 10. discrete (sling=0, hard pan=1) 11. discrete (0=no, 1=yes) 12. discrete (0=no, 1=yes) Continuous (0-15) 0=no, 1 or 2 = yes depending on the item	Miller, Miller, Trenholm, Grant, & Goodman, (2004)

Name of Measure	Construct	Items and Domains	Coding Continuous or discrete (range), coding	Reliability/ Validity Data
Wheelchair Issues	Wheelchair issues not identified in the SIT	1 domain with 5 dichotomous items: 1. not able to release set belt 2. sitting on a transfer sling 3. lap tray (full or half) 4. not able to release both brakes 5. wheelchair not capable of self-propulsion	Discrete (0-5) 0=no, 1=yes for each item	--
Wheelchair Skills Test Questionnaire (WST-Q) Environmental Factors	Wheelchair skills	57 items in one domain	Continuous (.00-1.00) (not applicable items not used) 0=fail, 1= pass	Mountain, Kirby, & Smith (2004)
Distance to nursing station	Distance to nursing station	One item	Continuous (0+) Measured in meters.	--

Name of Measure	Construct	Items and Domains	Coding Continuous or discrete (range), coding	Reliability/ Validity Data
Craig Hospital Inventory of Environmental Factors	Environ-mental Barriers to Participation	19 items from 4 domains: attitudes, services, physical barriers, and policy issues (work/school domains excluded). 4 questions modified (questions 2, 12, 15, 18: "home" replaced by "facility")	Continuous (0-152) (frequency: 0=never to daily=4; x 1=little problem or 2= big problem)	Whiteneck et al. (2004)
Resident Satisfaction Questionnaire	Satisfaction with the Facility	26, 4-choice ordinal items from 7 domains: room/unit, the facility, services, passing the time, staff care, resident involvement and overall rating	Continuous (0-78)	(Chou, Boldy, Lee, 2002).
Visits	Number of visits per week by friends and family	One item	Continuous (0+)	--

Name of Measure	Construct	Items and Domains	Coding Continuous or discrete (range), coding	Reliability/ Validity Data
Dependent Variables				
Late Life Function and Disability Instrument: Disability Component	Measures social participation	16 items from 2 dimensions (frequency of performance and limitation in performance) and 2 domains in each dimension. The frequency dimension includes a personal and social role domain. The limitation dimension includes an instrumental and management role domain.	Continuous (16-80 for frequency) (1=never to 5 = very often)	Jette et al. (2002)
Nursing Home Life Space Diameter	Frequency of mobility/ independent mobility in four life spaces	Measures frequency, and independence of mobility in 4 different life spaces: room, unit, facility and outdoors	Continuous (0-100) Frequency: (0=never and 5 => 3 time a day). Independence: (1=no, 2=yes)	Tinetti &, Ginter (1990)

Name of Measure	Construct	Items and Domains	Coding Continuous or discrete (range), coding	Reliability/ Validity Data
Satisfaction with Life Scale	Global Satisfaction with Life	5 items with a 7-point response scale from 1 domain	Continuous (7-35) 1= strongly disagree to 7 strongly agree	(Diener, Emmons, Larsen, & Griffin, 1985; Pavot, & Diener, 1993)

Comorbidity Index

Item number	Disease	Yes	No
1	Arthritis (rheumatoid and OA)		
2	Osteoporosis		
3	Asthma		
4	Chronic Obstructive Pulmonary Disease (COPD), acquired respiratory distress syndrome(ARDS), or emphysema		
5	Angina		
6	Congestive heart failure (or heart disease)		
7	Heart attack (myocardial infarct)		
8	Neurological disease (such as multiple sclerosis or Parkinson's)		
9	Stroke or TIA		
10	Peripheral vascular disease		
11	Diabetes type I and II		
12	Upper gastrointestinal disease (ulcer, hernia, reflux)		
13	Depression		
14	Anxiety or panic disorders		
15	Visual impairment (such as cataracts, glaucoma, macular degeneration)		
16	Hearing impairment (very hard of hearing, even with hearing aids)		
17	Degenerative disc disease (back disease, spinal stenosis or severe chronic back pain)		
18	Obesity and/or body mass index > 30 (weight in kg/height in meters ²) Height_____ (cm or inches) Weight_____ (kg or lbs) BMI=		

TOTAL

“yes” = 1

“no” = 0

Demographics Data and Additional Information

1. Age: _____
2. Sex: _____
3. Country of Birth _____
4. Date resident began living in the facility: _____
5. Date wheelchair use began: _____
6. Number of room mates: _____
7. Type of wheelchair (i.e., make, model, tilt-in-space, power, manual with foot rests, manual without foot rests): _____
8. Indicate whether wheelchair is
 - 1a. manual chair with foot rests
 - 1b. recliner chair manual
 - 1c. wheelchair without foot rests (feet on floor)
 2. Tilt in space wheelchair that can be self-propelled (excludes Broda and HTRs with feet off ground)
 3. a power wheelchair with out tilt (not scooter)
 - 3 b. power wheelchair with tilt
 4. Scooter
 5. Wheelchair that cannot be self-propelled
9. Ask if the resident has more than one chair. YES/NO
10. If yes record descriptive data below for it if the resident uses that chair more than twice per week. (Indicate which is the primary chair (used more than half the time))
11. Wheelchair equipment (i.e., cushion, arm tray, headrest):

<u>Cushions</u>	<u>Backs</u>
Air filled (RoHo)	Sling
Gel filled (jay cushion)	Personal back.
Ride (pressure elimination)	Base:
Foam	Sling

<p>Hybrid (many new cushions)</p> <p>Laptray? No=0 Yes=1</p>	<p>Hard Pan</p> <p>Headrest? No= 0 Yes= 1</p>
--	---

12. Does the resident own their own wheelchair (Yes/No)
13. Diagnoses: (not included in Comorbidity index)_____
14. Number of Medications from MAR (exclude vitamins and PRN):

15. Distance to nursing station (meters)_____
16. Number of friend and family visits in the last week_____
17. Please indicate the number of cigarettes you smoked in the last week_____
18. How many hours are you in your wheelchair everyday, on average? _____
19. Are you a veteran? Yes/No
20. How much are you charged per day for your room at the facility? _____
21. Wheelchair has seatbelt? Yes/ No
22. Can undo seatbelt? Yes/ No

Functional Independence Measure⁵

Self-Care

1. Eating
2. Grooming
3. Bathing
4. Dressing - Upper Body
5. Dressing - Lower Body
6. Toileting

Sphincter Control

7. Bladder Management
8. Bowel Management

Transfers

- 9 Bed, Chair, Wheelchair
10. Toilet

Locomotion

11. Walk/Wheelchair
12. Stairs

Motor Subtotal Score

Communication

13. Comprehension
14. Expression

Social Cognition

15. Social Interaction
- 16 Problem Solving
17. Memory

Socio-cognitive Subtotal Score

⁵ Full measure cannot be presented because of copyright. Tub transfer omitted.

General Health Question from SF-12

In general, would you say your health is?

Excellent

Very good

Good

Fair

Poor

Geriatric Depression Scale⁶

Introduction: I am going to ask your agreement or disagreement regarding the following questions. Please answer either yes or no.

Instructions: Circle the answer that best describes how you felt over the past week.

- | | | |
|--|------------|-----------|
| 1. Are you basically satisfied with your life? | yes | no |
| 2. Have you dropped many of your activities and interests? | yes | no |
| 3. Do you feel that your life is empty? | yes | no |
| 4. Do you often get bored? | yes | no |
| 5. Are you in good spirits most of the time? | yes | no |
| 6. Are you afraid that something bad is going to happen to you? | yes | no |
| 7. Do you feel happy most of the time? | yes | no |
| 8. Do you often feel helpless? | yes | no |
| 9. Do you prefer to stay at the nursing home, rather than going out and doing things outside the facility? | yes | no |
| 10. Do you feel that you have more problems with memory than most? | yes | no |
| 11. Do you think it is wonderful to be alive now? | yes | no |
| 12. Do you feel worthless the way you are now? | yes | no |
| 13. Do you feel full of energy? | yes | no |
| 14. Do you feel that your situation is hopeless? | yes | no |
| 15. Do you think that most people are better off than you are? | yes | no |

Total Score _____

Scoring: Score 1 point for each bolded answer.

⁶ Question 9 modified for residential care facility context.

Hearing from the Minimum Data Set (2.0)⁷

Hearing (with appliances if used)

0. HEARS ADEQUATELY-normal talk, TV, phone
1. MINIMAL DIFFICULTY when not in quiet setting
2. HEARS IN SPECIAL SITUATIONS ONLY—speaker has to adjust tonal quality and speak distinctly
3. HIGHLY IMPAIRED/absence of useful hearing

⁷ Available from http://www.cms.hhs.gov/MinimumDataSets20/025_ManualsAndForms.asp#TopOfPage.

Pain (from SF-12)

2. During the past four weeks, how much did pain interfere with your normal activities (including both work outside the home, housework and family activities)?

Not at all

Slightly

Moderately

Quite a bit

Extremely

Room Rates⁸

As of January 2008 these rates were:

Daily Rate	Remaining Annual Income*	Monthly Cost (x30)
\$29.90	\$0.00 - \$7,000	\$897.00
\$32.40	\$7,000.01 - \$9,000	\$972.00
\$36.00	\$9,000.01 - \$11,000	\$1,080.00
\$39.10	\$11,000.01 - \$13,000	\$1,173.00
\$43.40	\$13,000.01 - \$15,000	\$1,302.00
\$48.10	\$15,000.01 - \$18,000	\$1,443.00
\$52.50	\$18,000.01 - \$21,000	\$1,575.00
\$57.10	\$21,000.01 - \$24,000	\$1,713.00
\$61.80	\$24,000.01 - \$27,000	\$1,854.00
\$66.70	\$27,000.01 - \$30,000	\$2,001.00
\$71.80	\$30,000.01 or more	\$2,154.00

* Remaining Annual Income = Net Income (after-tax) - \$10,284

⁸ downloaded at [https://hermes.manulife.com/Canada/repsrcfm-dir.nsf/Public/ThecostoflongtermcareinBritishColumbia/\\$File/BC_LTC_CostReport.pdf](https://hermes.manulife.com/Canada/repsrcfm-dir.nsf/Public/ThecostoflongtermcareinBritishColumbia/$File/BC_LTC_CostReport.pdf)

(Standardized) Mini-mental State Exam⁹

ORIENTATION

_/5 What is the (year) (season) (date) (day) (month)? (1 point for each)

_/5 Where are we: (state) (county) (town) (hospital) (floor). (1 point for each)

REGISTRATION

_/3 Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them.

Give 1 point for each correct answer. Then repeat them until he learns all 3. Count trials and record.

Trials:

ATTENTION AND CALCULATION

_/5 Serial 7's. 1 point for each correct. Stop after 5 answers. Alternatively spell "world" backwards.

RECALL

_/3 Ask for the 3 objects repeated above. Give 1 point for each correct.

LANGUAGE

_/9 Name a pencil, and watch (2 points)

Repeat the following "No ifs, ands or buts." (1 point)

Follow a 3-stage command:

"Take a paper in your right hand, fold it in half, and put it on the floor"
(3 points)

Read and obey the following:

CLOSE YOUR EYES (1 point)

Write a sentence (1 point)

Copy design (1 point)

Total score: _/30

⁹ The SMMSE is not available because of copy right, but is a standardized version of the mini mental state exam (Folstein, Folstein, & McHugh, 1975).

Vision from the Minimum Data Set (2.0)¹⁰

Vision (able to see in adequate light and with glasses used)

0. ADEQUATE—sees fine detail, including regular print in newspapers/books
1. SLIGHTLY IMPAIRED—sees large print, but not regular print in newspapers/books
2. MODERATELY IMPAIRED—limited vision; not able to see newspaper headlines, but can identify objects
3. HIGHLY IMPAIRED—object identification in question, but eyes appear to follow objects
4. SEVERELY IMPAIRED—no vision or sees only light, colors or shapes; eyes do not appear to follow objects

¹⁰ Available from http://www.cms.hhs.gov/MinimumDataSets20/025_ManualsAndForms.asp#TopOfPage.

Seating Identification Tool

WITHIN THE LAST FOUR (4) WEEKS:	YES	NO
1) Has the individual had red areas on their bottom?	2	0
2) Has the individual had an open pressure sore on their bottom?	2	0
3) Has the individual had red areas on their back?	1	0
4) Has the individual had an open pressure sore on their back?	2	0
5) Has the individual reported or demonstrated behaviours that indicate they could be in discomfort or pain while sitting for any length of time? (such as moaning, grimacing, or agitation)	1	0
6) Has the individual had difficulty propelling their wheelchair?	1	0
7) Has the individual required repositioning as a result of sliding or leaning?	1	0
8) Has an anti-slide device such as a foam bolster, pommel, roll bar, posture pal, or posey restraint been used?	1	0
9) Have rolled blankets, pillows or homemade devices been used to prevent leaning?	1	0
10) Has the individual <i>not</i> been using a wheelchair seat cushion? (do not include linens, pillows, incontinence pads, or home made foam cushions)	2	0
11) Has the individual tipped their wheelchair or been at risk of tipping their wheelchair?	1	0

The overall score is the sum of all items.

Wheelchair Outcome Measure¹¹

Name / ID #: _____

THE WhOM

Part I: PARTICIPATION

Instructions for Administration:

Ask the client to identify activities they perform in their wheelchair that are important to them by asking the two questions outlined below. Have the client score the importance of these activities and then ask them to rate their current level of satisfaction in performing these activities. If the client has scored their satisfaction with an activity ≤ 7 , determine the underlying conditions (wheelchair/seating device or environmental barriers) that impair performance of this activity to assist with intervention planning.

1) Some people use their wheelchairs because they want to participate in activities in or around their home, such as preparing meals, watching TV, or gardening. What activities in your home would you use your wheelchair to perform?

Use this numerical scale to help fill in the table:										
0	1	2	3	4	5	6	7	8	9	10

Initial assessment Date:				Reassessment Date:	
Participation goals: <i>Eg. Making a meal Watching favourite TV show</i>	Importance <i>How important is this activity to you?</i> (0 - 10) 0 = Not at all important 10 = Extremely important	Satisfaction 1 <i>How satisfied are you with your current level of performance of this activity?</i> (0 - 10) 0 = Not satisfied at all 10 = Extremely satisfied	Importance x Satisfaction 1	Satisfaction 2 <i>How satisfied are you with your current level of performance of this activity?</i> (0 - 10) 0 = Not satisfied at all 10 = Extremely satisfied	Importance x Satisfaction 2
i.					
ii.					
iii.					
iv.					
v.					
Total of importance x satisfaction 1 scores =			Score 1 <input type="text"/>	Total of importance x satisfaction 2 scores =	
Change in satisfaction = Score 2			<input type="text"/>	- Score 1	<input type="text"/> = <input type="text"/>

Version #1: May 6 2004; Version #2: June 11, 2004

¹¹ Reprinted with permission

Name / ID #: _____

THE WhOM

2. Some people use their wheelchairs because they want to participate in activities outside of their home such as dog walking, going for coffee, to work or to the park. What activities outside of your home or in your community would you use your wheelchair to perform?

Use this numerical scale to help fill in the table:
 0 1 2 3 4 5 6 7 8 9 10

Initial assessment Date:				Reassessment Date:	
Participation goals: <i>Eg. Walking the dog Visiting my sister Watching a hockey game</i>	Importance <i>How important is this activity to you?</i> (0 - 10) 0 = Not at all important 10 = Extremely important	Satisfaction 1 <i>How satisfied are you with your current level of performance of this activity?</i> (0 - 10) 0 = Not satisfied at all 10 = Extremely satisfied	Importance x Satisfaction 1	Satisfaction 2 <i>How satisfied are you with your current level of performance of this activity?</i> (0 - 10) 0 = Not satisfied at all 10 = Extremely satisfied	Importance x Satisfaction 2
i.					
ii.					
iii.					
iv.					
v.					
			Total of importance x satisfaction 1 scores = <input style="width: 40px;" type="text"/> Score 1	Total of importance x satisfaction 2 scores = <input style="width: 40px;" type="text"/> Score 2	
			Change in satisfaction = Score 2 <input style="width: 40px;" type="text"/> - Score 1 <input style="width: 40px;" type="text"/> = <input style="width: 40px; border: 2px solid black;" type="text"/>		

Wheelchair Skills Test (3.2) - Manual Wheelchair (WST-Q)

#	Group	Individual Skills	Scores		Comments
1, 2	Brakes	-Apply	L	R	
3, 4		-Release	L	R	
5, 6	Armrests	-Move away	L	R	
7, 8		-Restore	L	R	
9, 10	Footrests	-Move away	L	R	
11, 12		-Restore	L	R	
13	Rolling	-Forward			
14		-Street crossing			
15		-Backward			
16, 17	Turns in place		L	R	
18, 19	Moving turns	-Forwards	L	R	
20, 21		-Backwards	L	R	
22, 23	Sideways manoeuvring		L	R	
24	Reaching	-Ground			
25		-High object			
26	Transfers	-Out			
27		-In			
28	Wheelchair	-Fold			
29		-Unfold			
30	Doors	-Open away			
31		-Open toward			
32	Obstacles	-2cm high			
33		-13cm high			
34, 35	Cross-slope		L	R	
36	Increased	-Carpet			
37	rolling resistance	-Gravel			
38	Pot-holes	-15cm across			

#	Group	Individual Skills	Scores	Comments
39		-30cm across		
40	Incline	-5°, ascent		
41		-5°, descent		
42		-7.5°, wheelie forward descent		
43	Level changes	-5cm, ascent		
44		-5cm, descent		
45		-15cm, ascent		
46		-15cm, descent		
47		-15cm, wheelie forward descent		
48-	Wheelie	-No-hands rest		
49	on level	-Stationary		
50	terrain	-Rolling forwards		
51		-Rolling backwards		
52, 53		-Turns in place	L R	
54, 55		-Moving turns forward	L R	
56, 57		-Moving turns backward	L R	

_____ % **Total Percentage Score** (total pass _____ /total number of applicable skills_____)

WSP 3.2 Form #4, WST-MW - January 27, 2006.

Wheelchair Skills Test (3.2) - Power Wheelchair (WST-Q-P)

#	Group	Skills	Scores		Comments
1	Controller	-on			
2		-off			
3		-select drive modes			
4		-accessories (e.g. horn)			
5	Controller	-move away			
6	access	-bring toward			
7	Power tilt	-backward			
8		-forward			
9	Power recline	-recline			
10		-elevate			
11	Motors	-engage			
12		-disengage			
13	Batteries	-charge			
14, 15	Armrests	-move away	L	R	
16, 17		-restore	L	R	
18, 19	Footrests	-move away	L	R	
20, 21		-restore	L	R	
22	Rolling	-forwards			
23		-backwards			
24, 25	Turns in place		L	R	
26, 27	Moving turns	-forward	L	R	
28,29		-backward	L	R	
30	Increased	-carpet			
31	rolling resistance	-gravel			
32, 33	Sideways maneuvering		L	R	
34	Reaching	-ground			
35		-high object			

#	Group	Skills	Scores	Comments
36	Transfers	-out		
37		-in		
38	Doors	-open away		
39		-open toward		
40	Obstacles	-2cm high		
41		-13cm high		
42	Street crossing			
43	Fold wheelchair			
44	Open wheelchair			
45, 46	Cross-slope		L	R
47	Incline	-5° ascent		
48		-5° descent		
49		-7.5° ascent		
50		-7.5° descent		
51		Pot-holes	-15cm across	
52		-30cm across		
53	Level changes	-5cm ascent		
54		-5cm descent		
55		-15cm ascent		
56		-15cm descent		
<p>_____ Total Percentage Score (total correct _____ /total number of applicable skills- _____)</p>				

WSP 3.2 Form #5, WST-P –January 28, 2006

Craig Hospital Inventory of Environmental Factors (CHIEF)

First, please tell me how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year, and tell me whether each item on the list below has been a problem **daily, weekly, monthly, less than monthly, or never**. If the item occurs, then answer the question as to how big a problem the item is with regard to your participation in the activities that matter to you.

		Daily	Weekly	Monthly	Monthly Less Than	Never	Big Problem	Little Problem
1. In the past 12 months, how often has the availability of transportation been a problem for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?							<input type="radio"/>	<input type="radio"/>
2. In the past 12 months, how often has the design and layout of your facility made it difficult to do what you want or need to do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?							<input type="radio"/>	<input type="radio"/>
3. In the past 12 months, how often has the design and layout of buildings and places you use in your community made it difficult to do what you want or need to do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?							<input type="radio"/>	<input type="radio"/>
4. In the past 12 months, how often has the natural environment – temperature, terrain, climate – made it difficult to do what you want	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		

	Daily	Weekly	Monthly	Monthly	Less Than Never	Big Problem	Little Problem
or need to do? When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
5. In the past 12 months, how often have other aspects of your surroundings – lighting, noise, crowds, etc – made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. In the past 12 months, how often has the information you wanted or needed not been available in a format you can use or understand? When this problem occurs has it been a big problem or a little problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. In the past 12 months, how often has the availability of health care services and medical care been a problem for you? When this problem occurs has it been a big problem or a little problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. In the past 12 months, how often has the lack of personal equipment or special adapted devices been a problem for you. Examples might include hearing aids, eyeglasses or wheelchairs. When this problem occurs has it been a big problem or a little problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Daily	Weekly	Monthly	Monthly	Less Than Never	Big Problem	Little Problem
9. In the past 12 months, how often has the lack of computer technology been a problem for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
10. In the past 12 months, how often did you need someone else's help in your facility and could not get it easily?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
11. In the past 12 months, how often did you need someone else's help in your community and could not get it easily?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
12. In the past 12 months, how often have other people's attitudes toward you been a problem at your facility?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
13. In the past 12 months, how often have other people's attitudes toward you been a problem in the community?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>

	Daily	Weekly	Monthly	Monthly	Less Than	Never	Big Problem	Little Problem
14. In the past 12 months, how often has a lack of support and encouragement from others in your facility been a problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?							<input type="radio"/>	<input type="radio"/>
15. In the past 12 months, how often has a lack of support and encouragement from others in your community been a problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?							<input type="radio"/>	<input type="radio"/>
16. In the past 12 months, how often did you experience prejudice or discrimination?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?							<input type="radio"/>	<input type="radio"/>
17. In the past 12 months, how often has the lack of programs and services in the community been a problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?							<input type="radio"/>	<input type="radio"/>
18. In the past 12 months, how often did the policies and rules of businesses and organizations make problems for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?							<input type="radio"/>	<input type="radio"/>

Little Problem
Big Problem
Never
Less Than
Monthly
Monthly
Weekly
Daily

19. In the past 12 months, how often did government programs and policies make it difficult to do what you want or need to do?

When this problem occurs has it been a big problem or a little problem?

Resident Satisfaction Questionnaire¹²

Satisfaction with Room

How would you rate the following?

The size of your room

The amount of storage space

The bathroom

How would you rate your room/unit overall?

Satisfaction with Home

Thinking now about the home as a whole, how would you rate?

Its design, for being able to get around easily

The lounge area

The dining room

The outside areas

Satisfaction with Social Interaction

Thinking about how you spend your time in the home:

Is there enough for you to do?

As far as having things to do, how would you rate the home?

Overall, how would you rate the social life in the home?

As far as being able to keep in touch with life outside, how would you rate the home?

Satisfaction with Meals Service

How would you rate the following?

Variety of food

Amount of food

Temperature of food

Meal times

Satisfaction with Staff Care

How would you rate the help you received from the home at the time you moved in?

Thinking about the staff now, how would you rate?

¹² The version used in the study could not be published due to copy right restrictions but is similar to the version, which appears in Chou, Boldy, and Lee (2002).

Their attitude toward you?

Their respect for your privacy?

The promptness with which they respond to your calls for help?

Satisfaction with Resident Involvement

Thinking now about opportunities for residents to be involved in things to do with the home and to have a say:

Does the home keep you informed enough about things that may affect you (e.g., staff changes, changes to services)?

Do you think residents have enough opportunities to put their views to the management (e.g., by resident meetings)?

Would you feel comfortable about approaching staff yourself to discuss a concern you had

about the home?

Do staff ever approach you to ask if you have any concerns you'd like to discuss?

Modified Late Life Function Disability Instrument: Disability Component¹³

Disability Questions

Disability Questions	How often do you?					To what extent do you feel limited in...?				
	Very	Often	Once in a	Almost	Never	Not at All	A little	Somewhat	A lot	Completely
D1. Keep (Keeping) in touch with others through letters, phone or email.	5	4	3	2	1	5	4	3	2	1
D2. Visit (Visiting) friends and family in their homes.	5	4	3	2	1	5	4	3	2	1
D3. Provide (Providing) care or assistance to others. This may include providing personal care, transportation, and running errands for family members or friends.	5	4	3	2	1	5	4	3	2	1
D4. Take (Taking) care of the inside of your room. This includes managing and taking responsibility for home making, laundry, room cleaning and minor room repairs.	5	4	3	2	1	5	4	3	2	1
D5. Help (Helping) out as a volunteer at the facility.	5	4	3	2	1	5	4	3	2	1
D6. Take (Taking) part in active recreation. This may include wheelchair bowling or swimming	5	4	3	2	1	5	4	3	2	1

¹³ Downloaded at <http://www.bu.edu/hdr/products/llfdi/index.html>. 3 questions were modified for residential care facility use: For question 8 the word “home” was changed to “room.” For question 11 the word “home” was changed to “facility.” For question 6, alternative examples were provided.

Disability Questions

	How often do you?					To what extent do you feel limited in...?				
	Very	Often	Once in a	Almost	Never	Not at All	A little	Somewhat	A lot	Completely
D7. Take (Taking) care of household business and finances. This may include managing and taking responsibility for your money, paying bills, dealing with a landlord or tenants, dealing with utility companies or governmental agencies.	5	4	3	2	1	5	4	3	2	1
D8. Take (Taking) care of your own health. This may include managing daily medications, following a special diet, scheduling doctor's appointments.	5	4	3	2	1	5	4	3	2	1
D9. Travel (Traveling) out of town for at least an overnight stay.	5	4	3	2	1	5	4	3	2	1
D10. Take (Taking) part in a regular fitness program. This may include walking for exercise, stationary biking, weight lifting, or exercise classes.	5	4	3	2	1	5	4	3	2	1
D11. Invite (Inviting) people into your facility for a meal or entertainment.	5	4	3	2	1	5	4	3	2	1
D12. Go (Going) out with others to public places such as restaurants or movies.	5	4	3	2	1	5	4	3	2	1
D13. Take (Taking) care of your own personal care needs. This includes bathing, dressing, and toileting.	5	4	3	2	1	5	4	3	2	1

Disability Questions

	How often do you?					To what extent do you feel limited in...?				
	Very	Often	Once in a	Almost	Never	Not at All	A little	Somewhat	A lot	Completely
D14. Take (Taking) part in organized social activities. This may include clubs, card playing, senior center events, community or religious groups.	5	4	3	2	1	5	4	3	2	1
D15. Take (Taking) care of local errands. This may include managing and taking responsibility for shopping for food and personal items, and going to the bank, library, or dry cleaner.	5	4	3	2	1	5	4	3	2	1
D16. Prepare (Preparing) meals for yourself. This includes planning, cooking, serving, and cleaning up.	5	4	3	2	1	5	4	3	2	1

Nursing Home Life-Space Diameter (NHLSD)

Introduction: “We want to find out where you move around.”

Within the last two weeks, how often have you moved around...

Would you say?

Do you move _____ (diameter) by yourself or does somebody push you?

Ind. mob Score

Diameter

	Never	Less than weekly	At least weekly	>2 times per week	1-3 times a day	>3 times a day
1. within your room?	0	1	2	3	4	5
2. Outside the room, within the unit	0	1	2	3	4	5
3. Outside the unit, throughout the facility	0	1	2	3	4	5
4. Outside the facility (i.e., left the facility)	0	1	2	3	4	5
Total score						

Basic Score

(2x) 1(x)

Self Other

Rater Sample Reference

Rater: “Within the last two weeks, how often have you moved around within your room? Would you say never, less than weekly, at least weekly, >2 times a week, 1-3 times per day or more than 3 times a day?”

Subject: “more than 2 times a week” (rater circle 3)

Rater: “Do you move around within your room by yourself or does somebody push you?”

Subject: “By myself” (rater insert checkmark in column)

Score : $1 \times 2 \times 3 = 6$: 1 (question #) \times 3 (frequency score) \times 2 (if self is checked multiply by 2 if other multiply by 1) = 6

Scoring

NHLSD = $1(\text{diameter } 1 \times \text{frequency } 1) + 2(\text{diameter } 2 \times \text{frequency } 2) + \dots$

Satisfaction with Life Scale (SWLS)

Below are five statements that you may agree or disagree with. Here is the 7 point scale, if you can read this, you can follow along. The responses are:

- 7 - Strongly agree
- 6 - Agree
- 5 - Slightly agree
- 4 - Neither agree nor disagree
- 3 - Slightly disagree
- 2 - Disagree
- 1 - Strongly disagree

Score	Statement
	In most ways my life is close to my ideal.
	The conditions of my life are excellent.
	I am satisfied with my life.
	So far I have gotten the important things I want in life.
	If I could live my life over, I would change almost nothing.

References

Brown, L.M., & Schinka, J.A. (2005). Developmental and initial validation of a 15-item informant version of the geriatric depression scale. *International Journal of Geriatric Psychiatry*, *20*, 911-918.

Centers for Medicare & Medicaid Services (2009). MDS 2.0 Manual and forms. Downloaded March 10, 2009 from http://www.cms.hhs.gov/MinimumDataSets20/025_ManualsAndForms.asp#TopOfPage.

Chou, S.C., Boldy, D.P., & Lee, A.H. (2002). Resident satisfaction and its components in residential aged care. *The Gerontologist*, *42*, 188-198.

D'Ath, P., Katona, P., Mullan, E., Evans, S., & Katona, C. (1994). Screening, Detection and Management of Depression in Elderly Primary Care Attenders. I: The Acceptability and Performance of the 15 Item Geriatric Depression Scale (GDS15) and the Development of Short Versions. *Family Practice*, *11*, 260-266.

Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment*, *49*, 71-75.

Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, *12*, 189-198.

Groll, D.L., To, T., Bombardier, C., & Wright, J.G. (2005). The development of a comorbidity index with physical function as the outcome. *Journal of Clinical Epidemiology*, *58*, 595-602.

Jenkinson, C., Layte, R., Jenkinson, D., Lawrence, K., Petersen, S., Paice, C., & Stradling, J. (1997). A shorter form health survey: can the SF-12 replicate results from the SF-36 in longitudinal studies? *Journal of Public Health Medicine*, *19*, 179-186.

Jette, A.M., Haley, S.M., Coster, W.J., Kooyoomjian, J.T., Levenson, S., Heeren, T., & Ashba, J. (2002). Late life function and disability instrument: I. Development and evaluation of the disability component. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *57*, M209-M216.

Kayser-Jones, J.S. (1981). *Old, alone, and neglected: Care of the aged in the United States and Scotland*. Berkley, CA: University of California Press.

Keith R.A., Granger, C.V., Hamilton, B.B., & Sherwin, F.S. (1987). The functional independence measure: A new tool for rehabilitation. *Advances in Clinical Rehabilitation*, *1*, 6-18.

Miller, W.C., Miller, F., Trenholm, K., Grant, D., & Goodman, K. (2004). Development and preliminary assessment of the measurement properties of the seating identification tool (SIT). *Clinical Rehabilitation, 18*, 317-325.

Molloy, D. W. (1999). *The Standardized Mini-Mental Status Exam (SMMSE)*. New Grange Press, Troy, Ontario, Canada.

Mountain, A.D., Kirby, R.L., & Smith, C. (2004). The wheelchair skills test, version 2.4: Validity of an algorithm-based questionnaire version. *Archives of Physical Medicine and Rehabilitation, 85*, 416-423.

Pavot, W., & Diener, E. (1993). Review of the Satisfaction with Life Scale. *Psychological Assessment, 5*, 164-172.

Tinetti, M.E. & Ginter, S.F. (1990). The nursing home life-space diameter. A measure of extent and frequency of mobility among nursing home residents. *Journal of the American Geriatrics Society, 38*, 1311-1315.

Whiteneck, G.G., Harrison-Felix, C.L., Mellick, D.C., Brooks, C.A., Charlifue, S.B., & Gerhart, K.A. (2004). Quantifying environmental factors: A measure of physical, attitudinal, service, productivity, and policy barriers. *Archives of Physical Medicine and Rehabilitation, 85*, 1324-1335.

Appendix 7

Table A7.1: Test-retest Intraclass Correlations Coefficients (ICCs) for Study Measures

Measure	Test-retest Reliability ICC (95% CI)	N
CHIEF	0.838 (0.643 - 0.931)	20
FIM	0.989 (0.973 - 0.996)	20
GDS	0.912 (0.795 - 0.963)	20
Hearing	0.857 (0.674 - 0.941)	19
Health	0.812 (0.592 - 0.919)	20
Hours in wheelchair	0.942 (0.837-0.980)	15
LLDI	0.943(0.869-.976	20
Pain interference	0.844 (0.656-0.934)	20
RSQ	0.859 (0.686 - 0.94)	20
SIT	0.885 (0.748 - 0.949)	20
SWLS	0.868 (0.703 - 0.944)	20
SMMSE	0.878 (0.734 - 0.946)	20
Wheelchair Issues	0.938 (0.818-0.980)	14
WST-Q	0.95 (0.876 - 0.981)	18
Vision	0.974 (0.936 - 0.99)	19
Visits	0.816(0.536 -.934	15

CHIEF = Craig Hospital Inventory of Environmental Factors, FIM = Functional Independence Measure, GDS = Geriatric Depression Scale, LLDI= Late Life Function and Disability Instrument: Disability Component (frequency), RSQ= Resident Satisfaction Questionnaire, SIT= Seating Identification Tool, SWLS=Satisfaction with Life Scale, WC= Wheelchair, WST-Q= Wheelchair Skills Test Questionnaire

Appendix 8

Table A8.1: Missing Data Analysis

Variable	N	Mean	Std. Deviation	Missing Count	%
SMMSE	266	15.44	10.693	4	1.5
Daily Rate	244	42.6535	16.16390	26	9.6
CHIEF Total	267	13.5730	15.87632	3	1.1
FIM Total	266	59.0338	25.54217	4	1.5
GDS Total	264	5.11	3.521	6	2.2
Health	266	1.91	1.076	4	1.5
LLDI Frequency	265	32.7396	10.18485	5	1.9
NHLSD Total	266	41.13	19.331	4	1.5
RSQ Total	264	47.66	11.398	6	2.2
Pain Interference	267	.91	1.109	3	1.1
SWLS	265	21.19	6.755	5	1.9
Length of Stay	266	32.8161	37.08827	4	1.5
“ of Wheelchair Use	260	45.0469	69.47083	10	3.7
WhoM Satisfaction	259	7.0808	2.27882	11	4.1
SIT Total	266	2.14	1.766	4	1.5
Comorbidity	266	3.08	1.942	4	1.5
Hearing	266	.55	.819	4	1.5
Vision	265	.77	1.086	5	1.9
WC Issues	257	.8677	1.15160	13	4.8
WST-Q Total	265	.3066	.21833	5	1.9
Broda	266			4	1.5
Powerchair	266			4	1.5

Abbreviations: Broda= wheelchair not capable of being self-propelled, CHIEF = Craig Hospital Inventory of Environmental Factors, CHIEF-phys. = CHIEF physical, CHIEF-pol. = CHIEF policies, FIM = Functional Independence Measure, GDS=Geriatric Depression Scale, NHLSD = Nursing Home Life Space Diameter, LLDI = Late Life Function and Disability Instrument: Disability Component, RSQ = Resident Satisfaction Questionnaire, SMMSE = Standardized,

Mini-Mental State Examination, SWLS= Satisfaction with Life Scale WhOM=Wheelchair Outcome Measure, WST-Q = Wheelchair Skills Test

Appendix 9 Table A9.1: Pearson Correlation Matrix of Independent and Dependent Variables for Total Sample

	NHLSD	LLDI	SWLS	hours in w/c	length WC	WC issues	WST-Q	WhOM Satisfaction	age	Comorbidity	FIM Total	FIM Motor	FIM Social Cognition	GDS Total	health	SMMSE	vision	CHIEF-phys.	CHIEF-pol.	RSQ total	visits
NHLSD	1.00	.56	.14	.13	.21	-.45	.66	.30	-.20	.09	.59	.55	.52	-.33	.17	.49	-.16	.11	.10	-.05	.09
LLDI	.56	1.00	.23	.16	.24	-.50	.59	.23	-.15	.17	.61	.53	.61	-.45	.19	.59	-.22	.24	.21	-.13	.04
SWLS	.14	.23	1.00	.00	.16	-.16	.15	.24	-.01	-.12	.18	.19	.12	-.47	.32	.09	-.15	-.11	-.13	.25	-.04
hours in w/c	.13	.16	.00	1.00	.04	-.12	.13	.02	.00	.10	.07	.10	.00	-.12	.05	-.06	-.08	.07	.10	.07	.02
length WC	.21	.24	.16	.04	1.00	-.10	.28	.11	-.17	-.11	.07	.03	.13	-.15	.12	.15	-.13	-.06	.03	.08	-.10
wc issues	-.45	-.50	-.16	-.12	-.10	1.00	-.68	-.20	-.01	-.06	-.67	-.64	-.57	.31	-.13	-.56	.05	-.09	-.01	.12	.12
WST-Q	.66	.59	.15	.12	.30	-.69	1.00	.27	-.20	.00	.76	.70	.69	-.38	.16	.66	-.23	.01	.04	-.10	-.10
WhOM	.30	.23	.24	.02	.11	-.20	.29	1.00	-.06	.08	.24	.21	.23	-.32	.19	.20	-.13	.01	-.07	.11	-.08
age	-.20	-.15	-.01	.00	-.17	-.01	-.18	-.06	1.00	-.01	-.09	-.05	-.13	.15	-.02	-.20	.13	-.15	-.03	-.03	-.07
Comorbidity	.09	.17	-.12	.10	-.11	-.06	.02	.08	-.01	1.00	.10	.06	.14	.02	-.14	.11	.20	.22	.15	-.09	.03
FIM Total	.59	.61	.18	.07	.07	-.67	.77	.24	-.09	.10	1.00	.96	.85	-.37	.23	.75	-.20	.03	-.04	-.10	-.05
FIM Motor	.55	.53	.19	.10	.03	-.64	.71	.21	-.05	.06	.96	1.00	.65	-.30	.21	.58	-.16	.00	-.06	-.05	-.02
FIM Social	.52	.61	.12	.00	.13	-.57	.69	.23	-.13	.14	.85	.65	1.00	-.41	.22	.86	-.22	.07	.00	-.15	-.09
GDS Total	-.33	-.45	-.47	-.12	-.15	.31	-.38	-.32	.15	.02	-.37	-.30	-.41	1.00	-.49	-.39	.21	.04	.07	-.12	-.01
health	.17	.19	.32	.05	.12	-.13	.17	.19	-.02	-.14	.23	.21	.22	-.49	1.00	.20	-.16	-.17	-.24	.29	-.01
SMMSE	.49	.59	.09	-.06	.15	-.56	.66	.20	-.20	.11	.75	.58	.86	-.39	.20	1.00	-.14	.08	.04	-.15	-.11
vision	-.16	-.22	-.15	-.08	-.13	.05	-.21	-.13	.13	.20	-.20	-.16	-.22	.21	-.16	-.14	1.00	.03	-.01	-.04	.00
CHIEF-phys.	.11	.24	-.11	.07	-.06	-.09	.01	.01	-.15	.22	.03	.00	.07	.04	-.17	.08	.03	1.00	.41	-.29	.08
CHIEF-pol.	.10	.21	-.13	.10	.03	-.01	.04	-.07	-.03	.15	-.04	-.06	.00	.07	-.24	.04	-.01	.41	1.00	-.31	-.03
RSQ total	-.05	-.13	.25	.07	.08	.12	-.09	.11	-.03	-.09	-.10	-.05	-.15	-.12	.29	-.15	-.04	-.29	-.31	1.00	.03
visits	.09	.04	-.04	.02	-.10	.12	-.10	-.08	-.07	.03	-.05	-.02	-.09	-.01	-.01	-.11	.00	.08	-.03	.03	1.00

Abbreviations: CHIEF = Craig Hospital Inventory of Environmental Factors, CHIEF-phys. = CHIEF physical, CHIEF-pol. = CHIEF policies, FIM = Functional Independence Measure, GDS=Geriatric Depression Scale, NHLSD = Nursing Home Life Space Diameter, LLDI = Late Life Function and Disability Instrument, RSQ = Resident Satisfaction Questionnaire, SMMSE = Standardized Mini-Mental State Examination, SWLS= Satisfaction with Life Scale WhOM=Wheelchair Outcome Measure, WST-Q = Wheelchair Skills Test, **Bold** = $p \leq .05$

Appendix 10 Table A10.1: Pearson Correlation Matrix of Independent and Dependent Variables for Self-responding Subjects

	NHLSD	LLDI	SWLS	hours in w/c	length WC	wc issues	WST-Q	WhOM Satisfaction	age	Comorbidity	FIM Total	FIM Motor	FIM Social Cognition	GDS Total	health	SMMSE	vision	CHIEF-phys.	CHIEF-pol.	RSQ total	visits
NHLSD	1.00	.34	.04	.17	.20	-.30	.58	.28	-.22	-.01	.36	.31	.31	-.16	-.01	.24	-.07	.10	.14	.07	.24
LLDI	.34	1.00	.18	.23	.26	-.19	.36	.12	-.17	.11	.24	.21	.21	-.31	.04	.21	-.13	.31	.29	-.02	.13
SWLS	.04	.18	1.00	.11	.18	.04	-.08	.11	.13	-.09	.09	.09	.03	-.45	.29	-.08	-.13	-.14	-.12	.32	.02
hours in w/c	.17	.23	.11	1.00	.11	-.21	.18	.12	-.03	.12	.10	.13	-.09	-.17	.08	-.15	-.03	.06	.09	.04	.05
length WC	.20	.26	.18	.11	1.00	-.10	.34	.11	-.19	-.15	-.01	-.05	.14	-.15	.13	.11	-.16	-.04	.03	.11	-.07
wc issues	-.30	-.19	.04	-.21	-.10	1.00	-.48	-.10	-.03	.07	-.39	-.42	-.01	.07	.13	-.01	-.17	-.04	-.05	.03	.07
WST-Q	.58	.34	-.07	.18	.37	-.48	1.00	.23	-.27	-.09	.47	.43	.32	-.12	-.07	.29	-.08	.04	.15	.02	.06
WhOM	.28	.12	.11	.12	.11	-.10	.28	1.00	-.02	.07	.19	.14	.23	-.31	.11	.27	.05	-.14	-.13	.18	-.05
age	-.22	-.17	.13	-.03	-.19	-.03	-.23	-.02	1.00	.01	-.02	.01	-.13	.02	.16	-.22	.15	-.27	-.07	.03	-.07
Comorbidity	-.01	.11	-.09	.12	-.15	.07	-.09	.06	.01	1.00	-.03	-.04	.01	.14	-.27	-.11	.30	.22	.26	-.08	.03
FIM Total	.36	.24	.09	.10	-.01	-.39	.50	.18	-.02	-.03	1.00	.97	.43	-.10	.01	.15	-.04	-.02	-.06	.08	.12
FIM Motor	.31	.21	.09	.13	-.05	-.42	.45	.14	.01	-.04	.97	1.00	.20	-.04	-.01	.02	-.02	-.04	-.06	.07	.08
FIM Social Cognition	.31	.21	.03	-.09	.14	-.01	.35	.23	-.13	.01	.43	.20	1.00	-.27	.06	.55	-.11	.05	-.03	.08	.19
GDS Total	-.16	-.31	-.45	-.17	-.15	.07	-.11	-.31	.02	.14	-.10	-.04	-.27	1.00	-.43	-.22	.17	.15	.16	-.32	-.02
health	-.01	.04	.29	.08	.13	.13	-.06	.11	.16	-.27	.01	-.01	.06	-.43	1.00	.02	-.20	-.33	-.34	.42	-.04
SMMSE	.24	.21	-.08	-.15	.11	-.01	.31	.27	-.22	-.11	.15	.02	.55	-.22	.02	1.00	-.15	.15	.04	.14	.25
vision	-.07	-.13	-.13	-.03	-.16	-.17	-.05	.05	.15	.30	-.04	-.02	-.11	.17	-.20	-.15	1.00	.01	.06	-.17	-.11
CHIEF-phys.	.10	.31	-.14	.06	-.04	-.04	.04	-.14	-.27	.22	-.02	-.04	.05	.15	-.33	.15	.01	1.00	.52	-.35	.17
CHIEF-pol.	.14	.29	-.12	.09	.03	-.05	.15	-.13	-.07	.26	-.06	-.06	-.03	.16	-.34	.04	.06	.52	1.00	-.30	-.04
RSQ total	.07	-.02	.32	.04	.11	.03	.02	.18	.03	-.08	.08	.07	.08	-.32	.42	.14	-.17	-.35	-.30	1.00	.08
visits	.24	.13	.02	.05	-.07	.07	.07	-.05	-.07	.03	.12	.08	.19	-.02	-.04	.25	-.11	.17	-.04	.08	1.00

Abbreviations: CHIEF = Craig Hospital Inventory of Environmental Factors, CHIEF-phys. = CHIEF physical, CHIEF-pol. = CHIEF policies, FIM = Functional Independence Measure, GDS=Geriatric Depression Scale NHLSD = Nursing Home Life Space Diameter, LLDI = Late Life Function and Disability Instrument: Disability Component, RSQ = Resident Satisfaction Questionnaire, SMMSE = Standardized Mini-Mental State Examination, SWLS= Satisfaction with Life Scale WhOM=Wheelchair Outcome Measure, WST-Q = Wheelchair Skills Test, **Bold** = $p \leq .05$

Appendix 11 Table A11.1: Pearson Correlation Matrix of Independent and Dependent Variables for Proxy Subjects

	NHLSD	LLDI	SWLS	hours in w/c	length WC	wc issues	WST-Q	WhOM Satisfaction	age	Comorbidity	FIM Total	FIM Motor	FIM Social Cognition	GDS Total	health	SMMSE	vision	CHIEF-phys.	CHIEF-pol.	RSQ total	visits
NHLSD	1.00	.60	.23	.14	-.06	-.36	.49	.27	.07	.20	.55	.58	.35	-.31	.32	.11	-.23	.16	-.01	-.08	.18
LLDI	.60	1.00	.23	.13	-.08	-.47	.44	.30	.14	.21	.59	.52	.55	-.36	.19	.40	-.28	.23	.09	-.11	.25
SWLS	.23	.23	1.00	-.17	.04	-.24	.37	.38	-.16	-.21	.20	.26	.05	-.49	.34	.01	-.16	-.06	-.17	.22	-.07
hours in w/c	.14	.13	-.17	1.00	-.24	-.12	.16	-.11	.05	.09	.15	.14	.13	-.12	.03	-.04	-.16	.09	.12	.11	-.02
length WC	-.06	-.08	.04	-.24	1.00	.12	-.07	.07	-.01	-.11	-.23	-.19	-.25	-.02	-.03	-.13	-.01	-.19	.02	.12	-.14
WC issues	-.36	-.47	-.24	-.12	.12	1.00	-.66	-.21	-.23	-.09	-.63	-.64	-.45	.21	-.17	-.43	.10	-.13	.07	.05	-.02
WST-Q	.48	.45	.37	.15	-.06	-.68	1.00	.25	.17	-.06	.72	.73	.53	-.34	.23	.31	-.35	-.05	-.21	-.04	-.01
WhOM	.27	.30	.38	-.11	.07	-.21	.25	1.00	-.05	.07	.23	.21	.20	-.28	.23	.12	-.31	.21	.03	.08	-.06
age	.07	.14	-.16	.05	-.01	-.23	.16	-.05	1.00	.02	.21	.20	.18	.15	-.18	.08	.05	.03	.05	-.17	-.16
Comorbidity	.20	.21	-.21	.09	-.11	-.09	-.03	.07	.02	1.00	.14	.09	.18	-.02	-.02	.17	.11	.22	-.05	-.07	.07
FIM Total	.55	.59	.20	.15	-.23	-.63	.73	.23	.21	.14	1.00	.94	.84	-.25	.29	.44	-.30	.09	-.15	-.06	.13
FIM Motor	.58	.52	.26	.14	-.19	-.64	.74	.21	.20	.09	.94	1.00	.60	-.24	.33	.30	-.25	.04	-.18	.00	.16
FIM Social Cognition	.35	.55	.05	.13	-.25	-.45	.54	.20	.18	.18	.84	.60	1.00	-.21	.14	.53	-.29	.14	-.06	-.13	.06
GDS Total	-.31	-.36	-.49	-.12	-.02	.21	-.34	-.28	.15	-.02	-.25	-.24	-.21	1.00	-.49	-.13	.18	-.07	-.01	-.06	-.14
health	.32	.19	.34	.03	-.03	-.17	.23	.23	-.18	-.02	.29	.33	.14	-.49	1.00	.06	-.06	.05	-.11	.22	.10
SMMSE	.11	.40	.01	-.04	-.13	-.43	.30	.12	.08	.17	.44	.30	.53	-.13	.06	1.00	.02	.20	.05	-.16	.04
vision	-.23	-.28	-.16	-.16	-.01	.10	-.34	-.31	.05	.11	-.30	-.25	-.29	.18	-.06	.02	1.00	.05	-.12	.07	.06
CHIEF-phys.	.16	.23	-.06	.09	-.19	-.13	-.06	.21	.03	.22	.09	.04	.14	-.07	.05	.20	.05	1.00	.22	-.20	-.03
CHIEF-pol.	-.01	.09	-.17	.12	.02	.07	-.21	.03	.05	-.05	-.15	-.18	-.06	-.01	-.11	.05	-.12	.22	1.00	-.35	-.01
RSQ total	-.08	-.11	.22	.11	.12	.05	-.04	.08	-.17	-.07	-.06	.00	-.13	-.06	.22	-.16	.07	-.20	-.35	1.00	-.06
visits	.18	.25	-.07	-.02	-.14	-.02	-.01	-.06	-.16	.07	.13	.16	.06	-.14	.10	.04	.06	-.03	-.01	-.06	1.00

Abbreviations: CHIEF = Craig Hospital Inventory of Environmental Factors, CHIEF-phys. = CHIEF physical, CHIEF-pol. = CHIEF policies, FIM = Functional Independence Measure, GDS=Geriatric Depression Scale NHLSD = Nursing Home Life Space Diameter, LLDI = Late Life Function and Disability Instrument: Disability Component, RSQ = Resident Satisfaction Questionnaire, SMMSE = Standardized Mini-Mental State Examination, SWLS= Satisfaction with Life Scale WhOM=Wheelchair Outcome Measure, WST-Q = Wheelchair Skills Test, **Bold** = $p \leq .0$