

DESIGNED FOR LIFE:
DISABLED/ENABLED AT HOME

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Dedication

I dedicate this thesis to my parents who have been my enablers, supporters and guinea pigs. May your rivers run freely with great life flow.

Abstract

Using a phenomenological hermeneutic methodology, this thesis describes the lived experience of people with mobility impairments in the context of their home environment. Nine individuals with mobility impairments were interviewed at length regarding their experiences in their homes. From the resulting narratives, the data were arranged under three thematic statements: Doing my thing, Being myself, and Evolving with my environment. The study highlights the interdependent nature of the person-environment-occupation relationship and reveals the potential for an enabling home design to affect all areas of human occupation (self-care, productivity and leisure). The efficient performance of self-care activities in the home emerged as being somewhat predictive of the extent to which participants were involved in the areas of productivity and leisure. This thesis offers support for the social model of disability and illuminates the need for incorporating universal design in all homes.

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Chapter 1

Introduction

Human rights and human diversity are concepts that Canada has embraced constitutionally with regard to culture and ethnicity, however within every race, religion, and age bracket, a group of people exist who have physical impairments. These people, in addition to overcoming the effects of their individual impairments on a daily basis, live in a culture that values physical wholeness, an environment geared toward a healthy, ambulatory male (Imrie, 2004). Though legislative advancements are apparent in the accessibility of many commercial buildings in the last 25 years (Crichton & Jongbloed, 1998), little action has been taken in Canada with regard to the home as a place to support occupational performance (performance of activities related to self-care, productivity and leisure). The profession of occupational therapy, with its focus on the person-environment-occupation fit, is well situated to assist in the established movement toward improved accessibility for everyone in the built environment (Canadian Association of Occupational Therapists, 2003). The ensuing chapter will describe this movement: its origins, key stakeholders, and current initiatives. It will conclude by revealing a gap in the literature that this thesis will attempt to address.

Disability Rights Movement: Beginnings

To date, improved accessibility and other human rights gains for people with impairments have primarily been the result of local, national, and international disability rights groups. In the early 1960's, these groups usually represented single impairments and focused much of their efforts "on service provision and medical alleviation and rehabilitation" (Hurst, 2003, p. 572), a reflection of the medical model of disability.

Subsequently, groups of people with various impairments began to come together, recognizing their socially imposed inferior position, and laid the ground work for what would become the Disability Rights Movement (Hurst, 2003), a movement toward a social relational understanding of disability (Thomas, C., 2002).

By 1980, many disability rights groups were well on their way to achieving an organized platform from which to create social change (Hurst, 2003). Founders of the Union of the Physically Impaired Against Segregation (UPIAS) in the United Kingdom, Finkelstein and Hunt contributed to the redefinition of disability as a form of social oppression (Thomas, C., 2002). According to the UPIAS, disability is “the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (UPIAS & The Disability Alliance, 1975, p. 14).

Terminology is an important tool in politicizing issues. The phrase, ‘disabled people’ as opposed to, ‘people with disabilities’ is used by disability activists to reflect the social roots of disability (Hammell, 2008) and will be used throughout this document. Hammell proposes the use of the term “occupational rights” by occupational therapists “to assert the right of all people to engage in meaningful occupations that contribute positively to their own well-being and the well-being of their communities” (p. 61).

Disability in Canada

Disabled people made up 12% of Canada’s total population in 2004 (Office for Disability Issues, 2004). Seniors (aged 65 and older) have the highest rate of disability and currently compose the fastest growing age bracket. In 1921, seniors represented one

in twenty in the overall Canadian population. By 2001 this proportion had risen to one in eight. These numbers are expected to rise to nearly one in four in 2041 (Health Canada & the Interdepartmental Committee on Aging and Seniors Issues [ICAS], 2002).

Considering this drastic increase in the senior's population and its inevitable effect on the rate of disability, a challenge exists to shape the typical home environment into that which facilitates occupational performance by the widest range of the population possible. The Center for Universal Design, North Carolina State University, defines universal design as "the design of products and environments to be usable by all people, to the greatest extent possible, without need for adaptation or specialized design" (Connell, Jones, Mace, Mueller, Mullick, Ostroff, et al., 1997). Universal Design addresses this challenge directly and offers a starting point for a shift in social understanding and policy, pertaining to the changing face of the population.

The Role of Occupational Therapy

In its 1997 guidelines, the Canadian Association of Occupational Therapy (CAOT) identifies the environment as one of three interdependent concepts; person, environment and occupation, which combine to produce occupational performance. The concepts are represented in a three dimensional, schematic diagram known as the Canadian Model of Occupational Performance (CMOP). Occupation is said to occur during the interaction of the person and the environment and is defined by CAOT (1997) as follows:

Occupation refers to groups of activities and tasks of everyday life, named, organized and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves

(self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity). (p. 34)

According to occupational therapy's basic assumptions, "occupation affects health and well-being; ...organizes time; ...brings meaning to life; ... and brings structure to living" (Townsend & Polatajko, 2007, p. 21). In the profession of occupational therapy, occupation is both a therapeutic medium and the profession's primary domain of concern; it is viewed as inseparable from the person and the environment (CAOT, 1997).

A subsequent CAOT publication (Townsend & Polatajko, 2007) expands the CMOP to include "engagement" in occupations, becoming the Canadian Model of Occupational Performance and Engagement (CMOP-E). Moving beyond performance of occupations to engagement is an important step in recognizing another way in which people create meaning in their lives regardless of their ability to perform occupations. One may gain meaning and satisfaction from engaging in a caring relationship with a friend, for example, without necessarily performing an occupation.

Central to occupational therapy's values and core concepts is client-centred practice (CAOT, 1997; Townsend & Polatajko, 2007). The profession strives to enable performance and engagement in occupations that are meaningful to the client, recognizing that "clients are experts regarding their own occupations" and involving them as "active partners in the occupational therapy process" (Townsend & Polatajko, 2007, p. 4). 'Enabling', as opposed to 'treating' a client, "supports involvement over caregiving, empowerment over dependence" (CAOT, 1997, p. 15). In an excerpt from the keynote address at the 1995 Annual Conference of the CAOT, Bonnie Sherr Klein, a

former occupational therapy client, “invited occupational therapists to become allies in partnership with clients” (CAOT, 1997, p. vii).

An effective avenue for enabling occupational performance when physical limitations exist involves changing the typical design of homes. Universal design is a concept supported by the CAOT (2003) and one of three movements toward improved accessibility addressed in this thesis. In a position statement published in the *Canadian Journal of Occupational Therapy* in 2003, the CAOT recommended that occupational therapists become active in research, planning, advocacy, and education regarding the use of universal design in our built environment.

Movements Toward Improved Accessibility

In addition to universal design, flexhousing and visitability are related movements toward the goal of improving accessibility in homes. The following section will outline their individual characteristics.

Universal Design

Compared to modifications, initial design to facilitate usability makes sense financially and provides access to a greater portion of the population (Canadian Mortgage and Housing Corporation [CMHC], 2008). Choosing such a design initially, helps to maintain self-identity and a sense of control in the event of predicted or unforeseen changes in one’s ability (Gitlin, 2003). The concept of universal design reflects human diversity and seeks to improve usability for all (Connell et al., 1997; Maisel, 2005; Sandhu, 2004). The seven principles of universal design are as follows:

1. Equitable Use

The design is useful and marketable to people with diverse abilities....

2. Flexibility in Use

The design accommodates a wide range of individual preferences and abilities....

3. Simple and Intuitive Use

Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level....

4. Perceptible Information

The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities....

5. Tolerance for Error

The design minimizes hazards and the adverse consequences of accidental or unintended actions....

6. Low Physical Effort

The design can be used efficiently and comfortably and with a minimum of fatigue....

7. Size and Space for Approach and Use

Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility. (Connell et al., 1997)

Practical application of these principles means incorporating features such as a level entry, 34-inch doorways and/or a raised dishwasher (East Metro Seniors Agenda for Independent Living, 2002). While maintaining aesthetic quality, these features often involve a slight increase in cost with several short and long term paybacks (CMHC, 2008). Promoting this concept to adults of all ages in the market for housing as well as builders, developers and architects is paramount.

Flexhousing

A related concept, put forth by the Canadian Mortgage and Housing Corporation (CMHC), is flexhousing. The CMHC (2004) defines flexhousing as “a concept in housing that incorporates, at the design and construction stage, the ability to make future changes easily and with minimum expense, to meet the evolving needs of its occupants”. It incorporates the principles of Adaptability, Accessibility, Affordability, and Healthy Housing. While the concepts of universal design and flexhousing differ slightly, both consider the likelihood of change in one’s physical capacity over time and address potential barriers to function that exist in most conventional homes. Another movement concerned with accessibility and inclusive design is visitability.

Visitability

Still in its infancy in Canada, the visitability movement in North America began in Atlanta, Georgia in 1986. Eleanor Smith, herself a wheelchair user, had a revelation one day while driving past yet another subdivision of newly-built homes with steps at their entrances. It occurred to her that “these homes could have all had access!” (Smith, 2003, p. 1). She joined forces with a local disability rights group to become Concrete Change, working toward basic accessibility of all newly built homes. This group adopted the term *visitability* in 1990 to describe their goal (Maisel, 2005).

According to Maisel (2005), visitability has three fundamental principles. First, it is a civil right, promoting the inclusion of people with mobility impairments in their communities and providing a means for social participation; second, access is affordable if implemented at the design stage as opposed to retrofitting; and third, “simplicity promotes implementation” (p. 14). A visitable home is one that meets the following three

conditions: “one zero-step entrance, doorways that are 32 inches wide and basic access to at least a half bath on the main floor” (p. 16). In the United States of America, several states and municipalities have visitability programs already in place for private homes with various specifications and methods of implementation (Maisel, 2005; Spegal & Liebig, 2003).

In Canada, the Canadian Centre on Disability Studies (CCDS) has recently published *Understanding the Status of Visitability in Canada* (2007), a starting point for the visitability movement in Canada. This project “produced the first Canadian website on visitable housing, the first Canadian survey on visitable housing and the first Canadian Think Tank on the subject” (CCDS, 2007). The CCDS is working closely with key individuals and organizations in the United States of America to advance their initiative, recognizing the housing needs of an aging population.

A Need for Change

Over the course of a lifetime it is likely that most people have been or will be affected by some form of mobility impairment, if only temporarily. The extent to which they are disabled depends, to a large degree, on the built environment. One might consider decreased strength and range of motion as impairments of mobility commonly associated with aging. Aging individuals with such mobility impairments are not generally described as disabled unless they are prevented from completing necessary tasks such as bath transfers or climbing stairs to enter the home. It stands to reason, then, that a universally designed home with features such as a walk-in shower and level entry, prevents the onset of disability.

From available research on visitability (CCDS, 2007; Maisel, 2005; Spegal & Liebig, 2003), it is clear that Canada is lagging behind other nations. Initiatives promoting universal design and visitability are putting enormous efforts into changing the typical home design to that which is more functional and inclusive. This shift makes sense and seems like a logical way to decrease disability in our aging population and improve the lives of people with mobility impairments. Organizations such as Concrete Change, the Center for Universal Design and the CMHC publish excellent technical information with regard to inclusive design and provide educational opportunities to key interest groups such as builders, developers and consumers. Seemingly absent from their campaigns and from the literature, however, is a body of research describing the effect of home design on the lives of people with mobility impairments. This absence has been identified by the CCDS (2007), and Gitlin (2003) who identifies the “lack of a critical mass of studies on home environments” (p. 2). Because of the relative lack of research pertaining specifically to this query, a wide range of research was drawn upon to frame this study.

Summary

With the help of the Disability Rights Movement, the concept of disability as a phenomenon of social origin has been created and used to achieve various human rights gains for disabled people. With the aging population, attention to home design that enables the performance of occupations by people with physical impairments is overdue. Occupational therapists, with their focus on the interaction of the person, environment, and occupation, can be valuable resources and advocates in the quest for improved accessibility in home design. Universal design, flexhousing and visitability are gaining

momentum as movements toward improved accessibility but require the backing of scholarly research to gain influence.

In order to better understand the effect of home design on people with mobility impairments, a qualitative study was performed, employing a phenomenological hermeneutic methodology. This research explored the lived experience of people with mobility impairments in the context of their home environment. The following chapter will review the available literature pertaining to and framing the research.

Chapter 2

Literature Review

In laying the groundwork for the ensuing research, there are four general areas within the literature that stood out as essential. Understanding disability theoretically and politically involves a review of prominent disability models as well as a history of disabling attitudes in society. Relevant models describing the person-environment relationship are described next with the addition of occupation as an essential concept. These models assist in interpreting the data and highlight the contextual richness of the phenomenon in question. On the topic of home, research concerning home modifications is presented to demonstrate the complexities involved with imposed changes on one's environment. Experiences of disabled people as homebuyers follows, further illustrating the social challenges with regard to housing and finally, a review of research regarding the meaning of home is presented as a comparative tool. Following is an overview of these four general areas concluding with the need for research in the area of home design.

Understanding Disability

The prominent disability models are presented below. In order to enhance the readers understanding of today's oppression of disabled people, an historical view is offered as to the origins of disabling attitudes in society.

Disability Models

Since the advent of the Disability Rights Movement in the 1970's there has been continued debate in the literature concerning a model to represent the phenomenon of disability. Despite more obscure psychological or charity models (Oliver, 1990) and more recent postmodernist views (Corker & Shakespeare, 2002), there has been a long standing

existence and occasional dialogue between two major camps within the study of disability, the medical or individual model and the social model (Thomas, C., 2004).

The long accepted medical or individual model of disability locates the cause of disability within the individual, linking impairment directly to disability while recognizing the lesser role that society plays in the negative experiences of disabled people (Bury, 2000). Oliver (1990) criticizes the ‘medicalisation’ of disability in the individual model, asserting that “disability is a social state and not a medical condition” (p. 3).

An interesting study by Australian Peter Siminski (2003) shows empirical support for the social model of disability. He uses quantitative data, “framed around a medical model of disability” (p. 707) from the Survey of Disability Ageing and Carers 1998 (SDAC 98) conducted by the Australian Bureau of Statistics. From a large sample of self-identified disabled people, interviews were conducted to reveal characteristics of the perceived disability. Resulting data indicated prevalence of disability by age, prevalence of ‘disabling conditions’ and life phases and selected ‘disabling mental conditions.’ Prevalence of disability by age showed a generally linear relationship, indicating increased rate of disability with advancing age as expected.

Within the prevalence of ‘disabling conditions’ and life phases, the relationship was much more complex, for instance, ‘disabling back problems’ “increases with age, but only between the ages of 15 and 64 for both men, and for women” (pp. 713-714). The rate after age 64 then sharply declines for both sexes, with more men experiencing ‘disabling back pain’ than women. Siminski (2003) points to the social expectations by

life phase (employment) and gender (males do more physical labour) as explanations for these results.

Similarly, 'disabling mental conditions' showed a significant peak in school aged children and subsequent decline in adulthood. While the conclusion is easily drawn that this peak is due to social expectations in the educational system, Siminski also mentions the possible effect of early screening and intervention by the medical system. Discourse over the causal properties of social vs. medical phenomena is not unique to this study.

From the social relational understanding of disability put forth by the UPIAS in 1975, Oliver formalised the social model of disability (Barnes, 1997; Thomas, C., 2004). The social model of disability identifies the cause of disability exclusively within society (Oliver, 1983, 1990). Oliver (1990) writes:

It is not individual limitations, of whatever kind, which are the cause of the problem (disability) but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation.

This model allows the emancipatory goals of disabled people to be realized (Siminski, 2003; Thomas, C., 2004).

The untimely release of the World Health Organization's (WHO) International Classification of Impairment, Disability and Handicap (ICIDH) in 1980, clearly reflecting the pervasive medical model, may have had a stifling effect on the Disability Movement's effort (Hurst, 2003). There was an immediate criticism by the disability community for the WHO's failure to reflect the impact of the physical, social and economic environment on disability in their definitions (Hurst, 2003). The WHO

eventually responded with a revision in 2001, the ICDH2, which, while appearing to take into account the limiting nature of the environment, continued to highlight the functional nature of the definition of disability, maintaining the locus of the disability within the individual, (Pfeiffer, 2000). Disability activists continue to reject this definition in favour of a social model that states that disability does not exist in the absence of the environment, in other words it is the individual's surroundings, built and social that is disabling (Oliver, 1983).

The WHO's most recent revision, International Classification of Function, Disability, and Health (ICF) "defines disability as the outcome of the interaction between impairment and functioning and the environment" (Hurst, 2003, p. 574). By reflecting further compromise between the two prevalent models, Hurst sees the ICF as an indication of change toward global acceptance of the role of the social environment which is critical for advancing public policy and upholding human rights for disabled people. Some disability activists, however, remain dissatisfied with this compromise (Michailakis, 2003; Pfeiffer, 2000). Pervasive, negative public attitudes continue to present the greatest obstacle for disabled people (Barnes, 1997).

Disabling Attitudes

To understand the development of disabling attitudes and practices in society, Colin Barnes (1997) emphasizes the need to understand history and its relationship to western culture. He begins by identifying negative public attitudes as presenting the biggest obstacle and identifying two explanations for this phenomenon. "The first, and older of the two, suggests that cultural perceptions of impairment are shaped by deep rooted psychological fears of the abnormal and the unknown" (pp. 3-4). The second,

which he expands upon in detail, is a materialist view “maintaining that disability and dependence are the ‘social creation’ of industrial capitalism” (p. 5), a socio/political theory of disability.

Barnes (1997) points out that Finkelstein, also using a materialist analysis, “divides history into three distinct phases” (p. 8). The first is associated with the pre-industrial era in Europe where the primary mode of production was agrarian and cottage based industry which didn’t exclude people with impairments. The second coincided with the large scale production of the industrial era in the nineteenth century. Factory work was geared to ‘able bodied norms’ and there was a shift to exclusion of people with impairments from economic and social activity, relocating many to residential institutions. Finkelstein’s third phase, often criticized for its excessive optimism and oversimplification, has reportedly just begun and, according to Barnes, involves the “liberation of disabled people from such oppression through the development and use of technology, and their working together with helpers and allies toward commonly held goals” (p. 8).

An emerging postmodernist voice is criticizing this simplistic view, demanding that culture be considered in the way people with impairments are viewed (Corker & Shakespeare, 2002). In Barnes’ materialist analysis (1997), he looks back to the ancient world of Greece and Rome and their influence on the formation of cultural attitudes toward people with impairments. He points to strong cultural values such as patriarchy, physical fitness, and bodily perfection as precipitating a negative attitude toward people with impairments and in fact writes of prescribed infanticide for children with impairments.

The analysis turns then to the Judean/Christian religions. Barnes (1997) points to the influence of Greek society in ancient Jewish culture, reporting that Jewish culture “perceived impairments as un-Godly and the consequence of wrongdoing” (p. 14). Judean religion did, however, prohibit infanticide and the Jewish derivative, Christianity, adopted a charitable view of the ‘sick’ or ‘less fortunate’. This charitable view, however, “effectively robbed disabled people of the claim to individuality and full human status” (p. 15).

Early English history is then cited as contributing to the objectification of disabled people, representing them in the arts as “objects of ridicule,” seen to be “the reflection of the devil” (Barnes, 1997, p. 17). By the eighteenth century, England was seeing the beginnings of industrialization and a new emphasis on ‘reason’ and ‘science.’ Similar to Finkelstein’s view, Barnes recognizes the industrial revolution of the nineteenth century as central to today’s established and systematic oppression of disabled people.

Oppression in the form of the built environment is evident in the typical design of homes that do not take into account the range of abilities that exists in the population. Environmental behavioural theorists, Lawton and Nahemow (1973), have contributed largely to the study of the environment and have provided a framework on which occupational therapy theory, concerning person-environment transaction, was built (Law, et al., 1996).

Person-Environment Relationship

Expanding on the Environmental Press Model (Lawton and Nahemow, 1973), several occupational therapy scholars have incorporated occupation as an essential component of the person-environment relationship (Law et al., 1996; CAOT, 1997;

Iwama, 2006). Below is a description of each model concluding with available research regarding occupation.

Environmental Press Model

Commonly found in the literature regarding the person-environment relationship is reference to Lawton and Nahemow's 1973 Environmental Press Model (Gitlin, Corcoran, Winter, Boyce, & Marcus, 1999; Gitlin, Mann, Tomit, & Marcus, 2001; Law et al., 1996; Messecar, 2000; Stark, 2001, 2004). In this model, Lawton and Nahemow (1973) define the person as a set of 'competences' in the domains of biological health, sensorimotor functioning, cognitive skill and ego strength. The environment is equated with the 'demand character' of the context in which the person behaves, borrowing the term 'environmental press' to describe it. Their schematic representation of the model is a graph, placing 'competences' on the vertical axis on a continuum from low to high and 'environmental press' on the horizontal axis on a weak to strong continuum. The body of the graph represents the behavioural and affective outcomes of the person-environment transactions. Given its predictive qualities and measurable definitions, this model has been useful to researchers (Law et al., 1996), however Lawton himself (1980) outlines a major limitation of the model as being the neglect of the person's perception of his or her environment. While recognizing the significance of this neglected dimension, he reiterates his ontological belief that the environment is composed of objective realities.

Person-Environment-Occupation Model

Unlike Lawton and Nahemow's (1973) Environmental Press Model, Law et al.'s (1996) Person-Environment-Occupation Model considers each domain of the

environment: cultural, socio-economic, institutional, physical, and social from the perspective of the individual or group in question. They have taken a transactive approach to the study of the person–environment relationship which assumes an interdependence of the person, the environment, and a third dimension, occupation. These major concepts are each represented within their own circle inter-related, or overlapping inside a cylinder. The space in the cylinder surrounding the circles represents the context within which the transactions take place. This cylinder, when extended, represents the ongoing development over the lifespan. The space in which the circles overlap denotes the outcome of the transaction between the person, environment and occupation which is occupational performance (Law et al., 1996). Occupational performance is central to the profession of occupational therapy (CAOT, 1997).

Canadian Model of Occupational Performance

In 1997, the CAOT published a guideline that served as a teaching tool for students as well as a gold standard for practitioners. It presented the Canadian Model of Occupational Performance (CMOP), a three dimensional figure depicting the dynamic relationship between the person, environment and occupation resulting in occupational performance. The schematic representation of the CMOP placed the concept of the person in a triangle surrounded by occupation (self-care, productivity and leisure) and the environment with its physical, institutional, cultural and social dimensions. The corners of the triangle, representing the cognitive, affective and physical components of the person, extend through occupation into the environment demonstrating the interdependence of these three dimensions. According to Law et al. (1996), “Occupational therapy theory, research and practice have moved from a biomedical

model based on principles of cause and effect, to a transactive model of occupational performance” (p. 10).

Kawa Model

Further displaying the connectedness of dimensions contributing to life is Iwama’s Kawa Model. Michael Iwama, a Japanese associate professor in the Department of Occupational Science and Occupational Therapy at the University of Toronto, performed a grounded theory project with the intention of developing a culturally relevant model for occupational therapists. He identified the lack of understanding and disillusionment of Japanese occupational therapists with Western-based theory, highlighting the collective will of Japanese people as opposed to Western individualism (Iwama, 2006). His model moved beyond the use of boxes and arrows to the metaphoric use of a river (*kawa* in Japanese) to represent the interactions of various dimensions of life.

Water, in this metaphor, represents life energy or life flow. The walls and bottom of the river signify the social and physical environment. Rocks symbolize life circumstance and driftwood can be thought of as one’s assets and liabilities (Iwama, 2006). “The spaces through which life flows, is representative of ‘occupation’ (p. 151). It is the job of the occupational therapist to look for opportunities to increase the flow by looking at the entire context of the river and anticipating the overall effect of the change to any one dimension. In this sense it is difficult to analyze an individual’s experience in the home environment without considering occupation. Two recent studies have explored occupation, illustrating its contribution to personal identity and quality of life. A third examines conditions found to influence occupational life.

Occupation

Griffith, Caron, Desrosiers and Thibeault (2007) recently used a grounded theory approach to investigate the process of giving meaning to occupation from the perspective of community-dwelling older adults with autonomy loss. The resulting theory illuminates the “relationship between one’s identity and the occupations which the person finds meaningful” (p.82). Following a “loss of autonomy, a process of adjusting to one’s identity occurs over time, involving social, psychological and spiritual aspects of the person” (p. 83).

Hammell (2007a) completed a meta-synthesis of qualitative findings from seven papers concerning quality of life after spinal cord injury. Ten main concepts were identified as contributing to quality of life in this population including “responsibility for, and control over one’s life...occupation and ability to contribute...environmental context...and self-worth.” She goes on to identify relationships between these factors. “The synthesis noted the interrelationship between the resources of the environment...and the ability both to engage in meaningful occupations and to assume responsibility and control over one’s life” (p. 135).

In a study to describe how disabled people experience their occupational lives in the home environment, Larsson Lund and Nygard (2004) used a constant comparative method to analyse interviews with thirteen disabled people. Of the conditions found to influence occupational life in the home environment for disabled people, support from social services personnel and from people close to them was the most significant. “The reason for this was that the other conditions, such as their impairment and inaccessibility in the home, were experienced as being more difficult to change” (p. 245). Research

regarding home modifications illustrates the complexities involved with prescribing environmental changes in the home are addressed below.

On the Topic of Home

Research concerning *the topic of home* included studies of home modifications, disabled homebuyers, and the meaning of home. The meaning of home for the general population and for disabled people is addressed.

Home Modifications

In a sample of community-based frail elderly subjects, Gitlin, et al. (2001) identified the mean number of environmental barriers in the home as 13.4. Factors found to be associated with the presence of environmental problems were age, gender, race, level of disability and pain. “The young-old, females and minority individuals were more likely to experience environmental problems” (p. 784), as were those with higher levels of disability and pain. Data from this 2001 study, “lend support for Lawton’s docility hypothesis that suggests that environments pose increasing difficulty as competencies decline” (p. 784).

The cost of home modifications required as physical abilities decline with aging, trauma, or disease, often exceeds that which is covered under government programs and charitable organizations (Office for Disability Issues, 2004). This leaves the home owner, who is often on a fixed income, with much of the financial burden of modifying his or her environment to enable occupational performance. Once financial hurdles are overcome, changing a home to accommodate different levels of ability has its benefits and drawbacks. One issue to consider is the disabled person’s, caregiver’s and/ or family member’s acceptance of suggested changes from community health professionals.

The extent to which recommended physical changes in the home environment are successful in enabling occupational performance is variable and depends on many factors. There can be a sense of loss of control associated with imposed environmental changes (Despres, 1991; Gitlin, 2003; Somerville, 1997), especially when brought on by failing health or disease progression which itself is difficult to accept. Gitlin et al. (1999) and Messecar (2000) make reference to Lawton's Environmental Press Model which suggests that a person's ability to tolerate demands of the environment depends on their total competencies. When competencies diminish the range of press a person can tolerate narrows. Press beyond that range can have negative impacts (Lawton & Nahemow, 1973).

It is important, when practicing occupational therapy in the community setting, that the therapist's assessment and intervention, beginning with entering the home, preserves the client's sense of control, privacy, and self-identity (Imrie, 2004). It is through careful consideration of social, environmental, personal and economic components, using a client-centred approach, that the assessment and intervention must proceed (CAOT, 1997; Rogers, 1980). Several studies have identified factors that contribute to acceptance of home modifications and adaptive equipment by caregivers and community-living older people (Gitlin et al., 1999; Mathieson, Jacobs Kronenfeld & Keith 2002; Messecar, 2000; Sheldon & Teaford, 2002). These factors include health and functional status, financial resources, attributes of the modification (e.g., ease of installation), gender (i.e., female), and depressive symptoms.

Increased participation and adherence to treatment (home modifications) were associated with poor health and functional status in the mild and moderately impaired

cases but this association began to decrease with more severe impairments (Gitlin et al., 1999). Existence of depressive symptoms, contrary to these authors' hypothesis, indicated poor participation and adherence. These results may reflect environmental press beyond the range that is tolerable according to Lawton and Nahemow's Environmental Press Model if we take into consideration the social press imposed by the interventionist. Interestingly, increased financial resources, predicted to be associated with acceptance in Mathieson et al.'s (2002) study, were associated with decreased acceptance. Gitlin et al. (1999) cite Gitlin, Luborsky, and Schemm's (1998) study showing that "some modifications are perceived as upsetting and socially stigmatizing such that their use may be rejected" (p. 370), a reflection of negative public attitudes toward people with physical impairments. Social exclusion is a reality for many disabled people and is evident at several levels with regard to housing. Current realities for disabled homebuyers will be considered next through two recent studies in the United Kingdom.

Disabled Homebuyers

Burns (2004) "explores the processes of negotiation which take place between disabled house buyers and house builders during the purchase of new-build property" (p. 765). Drawing on participants of a larger study, Burns uses semi-structured interviews with 31 self-identified disabled people who are currently in the process of purchasing or have successfully purchased homes. Burns' analysis of the data revealed a dichotomy concerning the house building industry's conceptualization of disabled people. She organizes these conceptualizations as; 'difference as Other' and 'difference as Heterogeneity.'

‘Difference as Other’ refers to the labelling of people with impairments as *primarily* different from the able-bodied norm while negating individual diversity within that group (Burns, 2004). Research participants with an experience related to Otherness reported a myriad of barriers ranging from physical inaccessibility and dismissal of alterations to plans, to a seeming disregard of disabled people as potential homeowners. Many with this experience abandoned the idea of new-build property in favour of an existing structure with potential for adaptation.

Conversely, ‘difference as Heterogeneity’ refers to the recognition of human diversity and the effects that the built environment can have on embodied differences. House builders with this conceptualization tended to view the customer as the expert and enlisted this expertise in the redesign of the home to meet his or her needs. Additional research by Thomas, P. (2004) revealed less encouraging results.

A multiple case study of 11 people with mobility impairments who had the experience of accessing the owner occupation market was completed. Through analysis of the data, Thomas also reports a trend toward disregard of disabled people as potential homeowners and reveals physical, attitudinal, and systemic barriers in the large majority of cases. These barriers were encountered in “estate agents, sales offices and the viewing of property” (Thomas, P., 2004, p. 784). In closing, Thomas suggests:

In order for disabled people with mobility impairments to take part on equal terms in the owner occupation market they need to be taken into account in the design of new and refurbished homes for sale. This requires certain minimum standards to provide key features of:

- level access to and within properties,

- strengthened walls to allow the installation of a lift or other fitments,
- space to allow flexibility of use, circulation and storage. (p. 792)

In other words, Thomas suggests a more universal design. The design of a home affects the way in which it is experienced by its occupant. The meaning of home will be considered next, both by the general population and by people with mobility impairments.

The Meaning of Home

In considering a theoretical stance from which to study the meaning of home, Somerville (1997) offers a review of existing theories and advances a hybrid of two he feels best capture the often complex nature of the meaning of home, naming it social phenomenology. The social approach examines meaning through the dynamics of social relations while phenomenology focuses on the construction of experience and action: “Essentially, it is argued that our understanding of home is constructed both through dialectics of phenomenology and through dynamics of social relations, in processes which cannot be broken down into separate ‘phenomenological’ and ‘social’ constituents” (p. 227).

Imrie (2004) provides additional support for this hybrid approach, crediting sociology with expanding the meanings of home with regard to categories such as gender and ethnicity but criticizing them as incomplete because they neglect “how specific bodily or physiological phenomena interact with dwellings to produce personal experiences of, and generate particular meanings about the home” (p. 747).

In a review of the literature, Despres (1991) identifies and expands upon ten repeated concepts from empirical research on the meaning of home:

Home as Security and Control....Home as reflection of One's Ideas and Values....Home as Acting Upon and Modifying One's Dwelling....Home as Permanence and Continuity....Home as Relationships with Family and Friends....Home as Center of Activities (independence)....Home as a Refuge from the Outside World (haven or sanctuary, place of privacy)....Home as Indicator of Personal Status....Home as Material Structure....Home as a Place to Own. (pp. 97-99)

Though agreeing with the repeated themes, Somerville (1997) criticises Despres for her lack of theoretical framework behind the meanings. They do, however, provide an interesting backdrop when considering the meaning of home for disabled people.

To echo the sentiment of others concerned with studying the meaning of home, a physical dwelling is not necessarily a 'home' (Annison, 2000; Harrison, 2004; Imrie, 2004). According to Harrison (2004), housing is a "complex mix of socio-economic and physical factors" (p. 692). In conducting research on physical characteristics of the home one must proceed with informed caution as to the contributing socio-economic factors in creating meaning for individuals. Harrison (2004) provides a list of such factors that affect how the physical environment is 'realised'. "Demographic conditions,...fear of crime" and "effects of hostilities to those perceived as 'different'" (p.702) are examples of these factors.

Imrie (2004) provides interesting insight into the misfit between 'ideal' conceptions of home and the realities of people with impairments occupying, in large part, homes built with the average, healthy, middle-aged male in mind. He identifies, for example, "conceptions of the home as a haven, or a place of privacy, security,

independence and control” as incongruent with many disabled peoples’ experience (p. 746). Imrie’s study involves interviews with 20 individuals with various mobility impairments who “were willing to talk about aspects of disability and domestic design” (p. 749). He organizes and presents his discussion of the data in three sections:

The first section develops and evaluates the argument that the design of home environments interacts with impairment to produce, more often than not, a series of spaces that are rarely sensitised to the needs of disabled people...The second section considers how far, and in what ways, dominant representations of the ideal home, such as privacy, security and sanctuary, accord with disabled peoples’ experiences of their homes. The final section develops the argument that disabled people are not necessarily passive victims of insensitive domestic design but, depending on social, personal and material resources, are able to influence aspects of the design and usability of the home environment. (pp. 749-750)

Much of the space and/or features in the respondents’ homes were unusable to them. This ranged from kitchens to bathrooms to positioning of windows in the case of wheelchair users and ease of movement throughout the home (Imrie, 2004). “For most respondents, living in the home is achieved by accepting, and adapting to, the standards of design that reflect the primacy of non-impaired bodies” (Imrie, 2004, p. 752). This demonstrates the absence of planning for human diversity so evident in the home builders/designers market (Burns, 2004; Thomas, P., 2004).

With regard to ascribed meanings in the home, Imrie (2004) found that, due to factors such as inaccessibility elsewhere and negative social experiences, the home was often seen as a place of confinement rather than haven or sanctuary by the respondents.

Similarly, a passage from one respondent quite vividly describes the lack of privacy she often feels in her home, specifically in using the bathroom even though she lives alone:

I can't take the wheelchair in, I have to stand, I can't close the door as the chair blocks it and the front door's there and everyone in the family has a key, so I mean, it's not ideal and anyone could come in at any time. (p. 755)

The same issue, lack of privacy, was described by others receiving care especially from agency workers and sometimes family members.

Imrie (2004) points out that although the social model of disability often portrays disabled people as 'victims' of inaccessible environments, his experience in this study and elsewhere has been that disabled people tend to be proactive and resourceful in overcoming barriers imposed by society and specifically the built world. This statement supports the personal control theory, briefly reviewed by Gitlin (2003), which suggests new directions for conducting research on home environments. The personal control theory "contends that individuals tend to be motivated to maintain control over difficult life situations and is based on the premise that 'control' is a human imperative" (Gitlin, 2003, p. 633).

Summary

In a government document on aging, a challenge is identified "to develop the most effective strategies to expand the disability-free years of life" (Health Canada & ICAS, 2002, p. 26). Viewing disability as a function of the environment, a logical strategy in light of the aging population is to promote exposure to and acceptance of universal design by all ages and abilities. Though housing research is abundant for the general population, people with impairments are generally left out at the research and

design stage (Imrie, 2004). Apparent from the research on home modifications, there are numerous factors contributing to the acceptance and perceived benefit of environmental changes in the home (Gitlin et al., 1999; Mathieson et al., 2002; Sheldon & Teaford, 2002). Research regarding the experience of people with mobility impairments in their home environment is scant while that focusing on universally designed homes is virtually nonexistent.

From a social relational perspective of disability, Thomas, C., (2002) writes, “the lives of people with impairment are profoundly shaped by the interaction of disability and impairment effects, and in lived experience these join together with other dimensions of individuals’ social positioning (gender, ‘race,’ age, class, sexuality)” (p. 20). Numerous social factors affect how the physical environment is experienced (Harrison, 2004). Accordingly, a phenomenological, hermeneutics method will be employed for this research which values these multiple dimensions, or the research participant’s ‘horizon,’ as central to the interpretation. These concepts will be expanded upon in the following chapter.

Chapter 3

Research Methodology

It is of utmost importance in the planning stage of research to carefully consider one's paradigmatic orientation. As outlined by Guba and Lincoln (1998), this can be accomplished by considering "three fundamental questions" (p. 201), questions concerning one's ontological, epistemological, and methodological assumptions.

Ontological Assumptions

Ontology is concerned with what is real and what can be known (Guba & Lincoln, 1998). Consistent with the constructivist view outlined by Guba and Lincoln, the research in question assumes that realities are relative, they are "intangible mental constructions, socially and experientially based, local and specific in nature...and dependent for their form and content on the individual person or groups holding the constructions" (p. 206). It is the reality, the 'lived experience' as conveyed by the participants' stories in the context of their surroundings that is of interest. Without context, the phenomenon in question does not exist.

Epistemological Assumptions

Epistemological considerations are next. The method by which knowledge is gained, again consistent with the constructivist view (Guba & Lincoln, 1998), is through interactive dialogue between the researcher and the research participants, "findings are actually created as the investigation proceeds" (p. 207). It is through an interactive, collaborative process that insight into the researched phenomenon is gained. Unlike the subject/object dichotomy of the positivist/postpositivist paradigms, knowledge will be gained through telling, hearing, and interpreting narratives.

Methodological Assumptions

Reflecting the interconnectedness of Guba and Lincoln's "three fundamental questions" (1998, p. 201), it follows that the methodological question is answered with a preference for a phenomenological hermeneutic methodology. In this design, the researcher interprets or points to the common themes reflected in the participants' accounts of their everyday experiences with the hope of creating more informed and sophisticated constructions (Guba & Lincoln, 1998; Lopez & Willis, 2004).

In order to capture the lived experience of being 'disabled' or 'enabled' in one's home environment, a phenomenological, hermeneutics approach has been chosen. As stated by Seamon (n.d.), "a phenomenological approach emphasizes that the material world plays a significant role in the quality of human life exactly because human beings are always everywhere immersed in their worlds, which in part is physical" (p. 23). It follows, then, that a positivist approach, one that isolates the object of study, does not lend itself to the study of disability and can be seen as oppressive in itself (Stone & Priestly, 1996). Stone and Priestly caution that an interpretive approach can also be oppressive, in this case stemming from the researcher's role as expert, suggesting that the "knowledge and experience of disabled people doesn't count" (p. 701). They see interpretive research as based on the medical model, leaving no room for alternative paradigms.

Based on constructivist ontology and the social model of disability reviewed in Chapter 2, every attempt was made to accurately represent the themes of the research participants. A collaborative approach was used during the design of the research and at the analysis phase with the use of member checking (Creswell, 2003), affording special

sensitivity to the researcher-participant dichotomy. Hammell (2007b) suggests qualities of a proposed disability methodology that have been incorporated throughout this research. These qualities reflect research that:

- is built on respect and collaboration.
- is based on the priorities of disabled people so as to produce knowledge that they can use to make informed decisions.
- is based on a social theory of disability,
- focuses on person/environment interactions,
- challenges conventional assumptions about disability,
- includes an action component, and
- involves participants in evaluating the research process.

Phenomenology

Though phenomenology's roots can be traced back to the 18th century philosophies of Kant and Hegel, Edmund Husserl (1859-1958) developed the concept further as a method of gaining knowledge (Groenewald, 2004). Disillusioned by the positivist stronghold that prevailed, Husserl "rejected the belief that objects in the external world exist independently" (p. 4). Husserl's phenomenology sought to describe life as it is actually lived rather than adhere to the Cartesian tradition of studying objects in isolation, disconnected from the world (Groenewald, 2004; Jardine, 1990; Lopez & Willis, 2004; Moran, 2000). Instead, Husserl believed that "experience as perceived by human consciousness has value and should be an object of scientific study" (Lopez & Willis, 2004, p. 727).

According to van Manen (1990), phenomenology “attempts to gain insightful descriptions of the way we experience the world pre-reflectively, without taxonomizing, classifying, or abstracting it” (p. 9). Husserl described a ‘phenomenological reduction’ (Jardine, 1990; Lopez & Willis, 2004; Moran, 2000) whereby the researcher must put aside all prior knowledge and assumptions of the phenomena in question including social, cultural, and historical influences, in order to truly convey the essence of the lived experience of his or her subject. This ‘bracketing’ allows the researcher “to be attentive to that which is *given* in intuition” (Moran, 2000, p. 9).

Husserl believed that the essence of human experience would repeat itself in various subjects, revealing universal essences or eidetic structures, a univocal voice representing the true nature of a phenomenon, independent of context (Lopez & Willis, 2004). This phenomenologic reduction in the interest of scientific rigor and the assumed presence of universal essences, independent of context, point to the Cartesian influence in Husserl’s philosophy (Jardine 1990; Lopez & Willis 2004). Considering the interconnectedness of the person, environment and occupation in peoples’ lives (CAOT, 1997; Iwama, 2006; Law et al., 1996) the idea of universal essences independent of context is rejected in favour of a hermeneutic approach for this project.

Hermeneutics

Husserl’s student, Martin Heidegger broke free of this influence and adopted the practice of hermeneutics as a phenomenological approach to research. While continuing Husserl’s tradition of studying the lived experience, Heidegger’s assumptions and methods differed. Contrary to Husserl’s beliefs, Heidegger saw culture, society, and politics as impacting the individual’s freedom of choice. Lopez and Willis (2004) refer to

this concept as situated freedom, “an existential phenomenological concept that means that individuals are free to make choices, but their freedom is not absolute; it is circumscribed by the specific conditions of their daily lives” (p. 729). Sass (1988) describes Heidegger’s concept of ‘horizon’ as that which makes up the physical, social, cultural, and historical backdrop, which is “the medium of experience itself” (p. 242). Given the contextual significance of the proposed study, it seems necessary to use a hermeneutic approach with its kindred assumptions about the contextual influence on phenomena.

It is on similar grounds that Heidegger rejects Husserl’s phenomenologic reduction or concept of bracketing. Sass (1988) writes, “As Heidegger understands it, this aspect of everydayness is both too all-encompassing and too close to the human subject to be readily known or recognized” (p. 242). Thus Heidegger not only found this shedding of presuppositions impossible but saw pre-existing knowledge and suppositions, the researcher’s ‘horizon’, as essential for interpretation (Lopez & Willis, 2004). Sass describes a “productive view of understanding” whereby meaning “exists in the dialogue” and “legitimately depends, to a significant extent, on the person who listens” (pp. 252-253).

Hermeneutic inquiry is, by nature, interpretive rather than descriptive (Jardine, 1990; Lopez & Willis, 2004; Moran, 2000; Polkinghorne, 1983; Sass, 1988). According to Patton (2002), “Hermeneutics provides a theoretical framework for interpretative understanding, or meaning, with special attention to context and original purpose” (p. 114). “It goes beyond mere description of core concepts and essences to look for meanings embedded in common life practices” (Lopez & Willis, p. 728). It is hoped that

interpretation can be somewhat emancipatory when meanings are revealed by the researcher that were hidden, or too commonplace to see for the participants or those experiencing similar phenomena.

The use of narrative as the mode of data collection is central to the hermeneutic methodology. As Nixon (1992) points out, “we comprehend larger patterns through story” (p. 102). The interpretive circle, described by Patton (2002), illustrates how, through the process of interpretation, meanings are formulated by abstracting from the whole story individual parts then restoring them once again to reflect major themes. The following section describes the researcher’s horizon, the place from which the data is analyzed and interpreted.

The Researcher’s Horizon

It is from three different perspectives that this topic has specific relevance to me as the researcher: as an occupational therapist, as a daughter of someone with a mobility impairment, and as an aging member of society. As an occupational therapist I have a keen interest in the person-environment fit. Though I have been employed in numerous settings, it has been the community setting I find most interesting. Problem solving with clients in their own, familiar environment makes sense intuitively and allows the client to be the expert on his or her needs within the home. Though my work in the community setting consists largely of consultation on small environmental modifications and provision of adaptive equipment, I have observed a certain pride in those people that had ‘thought ahead’ and incorporated universal design concepts in their home in anticipation of their needs. More frequently, however, I have seen frustration and a sense of loss of control when an elderly couple are in crisis, for example, because one of them is no

longer able to navigate the stairs in their split level home that they purchased following their retirement from farming two years prior. I see, as well, the hesitation to make changes in a home that a client has resided in for many years, enduring pain and increased risk to maintain the home in its present state.

This hesitation is obvious to me personally as well. In 2003 my mother was diagnosed with rheumatoid arthritis at the age of 64. The disease progressed swiftly making performance of many of her usual roles too painful or unsafe to attempt. Though my training as an occupational therapist is seen by many, including her, to be advantageous in her current situation, acceptance of recommended changes to the home environment is slow. As reviewed in chapter 2, several factors are undoubtedly contributing to the resistance to environmental modifications.

Lastly, it is the recognition of the possibility of me or another member of my family encountering an impairment sometime over the life span that springs me into action. In addition, I have only to consider my extended family and friends and their ability to visit my home, something I highly value.

Research Procedure

A discussion of the research procedure employed will follow. It begins with the selection of participants, is followed by a description of the study sample, discusses the procedure used for data collection and analysis and concludes with ethical considerations with regard to this study.

Initial Selection of Participants

Recruitment of research participants was initially accomplished through referral by community occupational therapists in the Chinook Health Region. Selection of this purposive sample was based on the following inclusion criteria – participants must:

- be 18 years of age or older
- have some form of mobility impairment
- have chosen to live in a house that incorporates at least three universal design features (see Appendix A for list of features)
- be able to speak and comprehend English
- be able to articulate his/her current experience and to reflect on past experience in the home environment

A letter of invitation to participate (Appendix B) was provided to the community occupational therapists in the Chinook Health Region to be passed on to appropriate potential participants. The participants were asked to contact the researcher by phone or e-mail if interested in taking part in the study. Several potential participants instead asked that the occupational therapist pass on their phone number to the researcher. This was accommodated and these potential participants were contacted by the researcher. Telephone conversations with each participant ensured that criteria were met. The research format was explained, questions addressed, and a meeting was scheduled at a convenient location, usually their homes.

Subsequent Selection of Participants

After several months, and a couple of gentle reminders to the referral source, a total of four referrals had been received. Following consultation with the thesis

supervisor and the community liaison at the Canadian Paraplegic Association (CPA), and approval from the University of Lethbridge Human Subjects Research Committee, the CPA was added as an additional referral source in an effort to reach a greater number of people with mobility impairments.

In discussing the project with the community liaison at the CPA, herself a person with a mobility impairment, it was communicated that people with mobility impairments living in universally designed or accessible homes was the exception to the rule, in her experience. From past experience as a community occupational therapist, and considering the small number of referrals received, I concurred. Through consultation with thesis committee members, reflecting on the interviews completed to date and considering the scant information in the literature regarding people with mobility impairments' experiences in the home, a decision was made to broaden the population in question. The sample would now include people with mobility impairments living at home, regardless of its level of accessibility. It was felt that including people who did not necessarily live in accessible homes would situate the research closer to reality and provide an opportunity for comparison in some cases. In addition, changing the design of the research based on information from the disabled community reinforced the collaborative approach. Thus, the inclusion criteria became – participants must:

- be 18 years of age or older
- have some form of mobility impairment
- be able to speak and comprehend English
- be able to articulate his/her current experience and to reflect on past experience in the home environment

The Human Subjects Research Committee was again advised of the change and permission to proceed was granted.

Study Sample

The sample consisted of nine participants, five males and four females, ranging in age from 25 to 87. There were four participants recruited under the initial set of inclusion criteria. These four participants show a maximum degree of usability in their homes in Table 1. A subsequent set of five participants met the second set of inclusion criteria and show a range from minimum to moderate – maximum in the column describing the degree of usability of their homes. Each participant had basic access to their homes via level entry or ramp. Homes with several inconveniences, safety issues or unusable spaces were labelled as having minimum usability. As these qualities lessened, the degree of usability improved with maximum being the highest. Table 1 displays additional relevant information about participants (i.e. gender, age, marital status, diagnosis and annual income).

Table 1. *Participant Information*

Participant	Gender	Age	Marital Status	Diagnosis	Home Design Degree of Usability	Annual Income
George	M	69	M	Syringo myelia (degenerative neurological disorder)	Maximum	20,000
Jane	F	26	S	Paraplegia	Moderate	18,000
Michael	M	35	S	Spastic cerebral palsy	Minimum	11,000
Joe	M	51	M	Paraplegia, rheumatoid arthritis	Maximum	100,000
Ted	M	87	M	Paraplegia, hemiparesis, b/k amputation	Maximum	50,000
Cindy	F	40	M	Incomplete quadriplegia	Maximum	40,000- 50,000
Clair	F	25	S	Hypomyelinating neuropathy (degenerative neurological disorder)	Moderate	12,000
Anita	F	44	M	Waardenberg's syndrome, multiple traumas	Minimum	25,680
Greg	M	29	M	Paraplegia	Moderate- maximum	42,000

Data Collection

In accordance with Creswell's (2003) outline of procedure, data collection took the form of semi-structured interviews, incorporating open-ended questions that allowed the interview to evolve (see Appendix D). A second interview guide was created to be applicable to the newly recruited participants (see Appendix E). It should be noted that all participants were eligible for participation based on the second list of eligibility criteria; therefore the participants were not two distinct groups. Changes to the wording of the research question reflected this broadening of criteria. The original question: *What is the lived experience of people with mobility impairments who have chosen to incorporate universal design features in their home?* became: *What is the lived experience of people with mobility impairments in the context of their home environment?*

An attempt was made to incorporate a client-centred approach during the interview as outlined in *Enabling Occupation: An Occupational Therapy Perspective* (CAOT, 1997). In order to augment the narrative, spontaneous observations of the built environment were recorded, and when appropriate, the participant's ability to function within that environment. As Creswell (2003) suggests, a single page divided down the middle to separate descriptive and reflective notes was used. Interviews were recorded by a digital voice recorder and handwritten notes and observations were kept to supplement this information. Participants were given pseudonyms and audio files were transcribed verbatim by a professional transcriptionist following the signing of a confidentiality agreement. The transcripts were kept in a locked filing cabinet to which the researcher had exclusive access. The transcripts were reviewed for authenticity and audio files erased.

The willingness of the participants to share their experiences and the researcher's genuine interest led to rich conversations. In each case the participants were happy to provide responses to all questions and were open to further contact regarding the study.

Data Analysis

A data analysis technique described by Creswell (2003) was employed using a six-step procedure: 1) organize and prepare the data for analysis; 2) read through all data to obtain a general sense of the information and to reflect on its overall meaning; 3) use a coding process; 4) generate a description through the process of coding to form a small number of themes or categories; 5) advance how the description and themes will be represented in the narrative by using a narrative passage to convey findings of the analysis; and 6) interpret the data based on "the individual understanding that the inquirer brings to the study from his or her own culture, history, and experiences" (pp. 191-195).

Within this procedure reference was made to van Manen's (1990) four fundamental lifeworld themes or "existentials," these include "lived space (spaciality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality)" (p. 101). Though not reflected directly in the findings, these lifeworld themes provided the researcher with a point of reference when considering each narrative passage.

Analysis of the data was ongoing throughout data collection. The transcripts were read in full as they were completed and general thoughts recorded in the margins. These thoughts were condensed and represented by phrases such as: Universal design adds convenience; Home as hub; and Making do... These phrases became topics and were divided into four groups based on similarity or relevance to one another. The transcripts

were re-read and coded according to the topics. While these phrases were useful in creating categories under the eventual themes, it was apparent that the analysis thus far lacked an organizational nature. The task then was to step back and look more generally at the data to pull out the themes from which the categories arise, completing the interpretive circle (Patton, 2002).

In each transcript the participants spoke about their home environment with reference to what they do, who they are, how they got to this place in life and where they intend to go from here. The concepts of doing, being, getting there and looking ahead were present throughout but seemed too simple and several attempts were made to create more sophisticated themes that, in the end, did not resonate. Following discussion with the thesis supervisor and an occupational therapy colleague, it was decided that these original concepts had merit. Once again the transcripts were revisited. The last two concepts (i.e. getting there and looking ahead) were condensed into one, and the three major themes were developed: Doing my thing; Being myself; and Evolving with my environment.

Use of member-checking (Creswell, 2003) was incorporated at this stage in the analysis by presenting themes gleaned from the data back to the participants for review and subsequent discussion. Themes were discussed with the participants via e-mail or telephone. Participants supported the themes and subsequent interviews were arranged with only two participants to expand on their initial interviews.

Once data collection was complete, the researcher began the arduous process of physically cutting out the coded segments of the transcripts according to the themes they represented and the topics they addressed. They were then compiled in an effort to

visualize support for the themes. Selecting the narrative passages to represent the themes followed.

Grouping excerpts from the transcripts by themes and topics allowed extraction of the most descriptive, eloquent, or raw passages to represent the data. An attempt was made to provide “rich, thick description” in the findings in order to draw in the reader in an experiential fashion (Creswell, 2003, p. 196). “Presenting negative or discrepant information” (p. 196) was also employed, for example most of the participants’ views on being disabled were contrary to what was expected by the researcher and are discussed in detail in the findings chapter.

Ethical Considerations

To ensure all aspects of the study complied with ethical standards for research involving human subjects, a research proposal was submitted first to the Ethics Committee at the Chinook Health Region and subsequently to the Human Subjects Research Committee at the University of Lethbridge and ethical approval obtained. Additional precautions were taken within the study to ensure rigorous compliance with ethical standards.

A letter of consent was provided to each participant for review (see Appendix F). They were given an opportunity to ask any questions with regard to the aims and methods of the study and the nature of their participation. They were advised of their ability to withdraw at any time without consequences. Anonymity and confidentiality were ensured through the use of pseudonyms and limited access to recordings and transcripts (by the researcher and transcriptionist only). The letters of consent were then signed by the

participants indicating their agreement to participate and a copy was left for their reference.

Audio-tapes were erased following the transcript's verification for accuracy. The name and phone number of the researcher's supervisor was supplied to each participant, to be available for any concerns the researcher was unable to address. In the unlikely event of emotional distress arising from the subject matter discussed, sources for referral were offered to affordable community agencies though none were accessed in the course of this study.

Summary

Using a constructivist paradigm (Guba & Lincoln, 1998), this research employed a phenomenological hermeneutics methodology to explore the lived experience of people with mobility impairments in the context of their home environment. The selection of participants was achieved by referral from community occupational therapists and the Canadian Paraplegic Association in the local health region. The study sample included nine individuals with mobility impairment living at home. Data collection involved semi-structured interviews which were recorded by voice recorder and later transcribed. Analysis of the data was performed using a six step, manual coding technique outlined by Creswell (2003). The research complied with ethical standards for human subject research at the Chinook Health Region and the University of Lethbridge and letters of consent were signed by each participant. The following chapter will introduce the participants and present the themes conveyed by their voices.

Chapter 4

Findings

In order to convey meaning through the participants' narratives it is necessary to provide descriptions of these people 'in context'. An introduction to each participant is provided, followed by the presentation of the themes gleaned from the data.

Participant Descriptions

Following are descriptions of the nine participants involved in this study. Comments on the 'fit' with their home environment are added to provide a deeper understanding of the manner in which they experience their homes.

George

George is a 68 year old man who lives with his wife on a cattle ranch outside a small town. He has a rare, progressive disease that affects his spinal cord and causes paralysis. He has been using a wheelchair for eighteen years and has only recently lost the ability to propel it manually. George is dependent on his wife for most of his self-care needs but maintains a functional role in the family ranch.

His home was designed and built in 1995 to be wheelchair accessible and functional for him and his wife. The home has a level entry from the garage, a large bathroom off the master bedroom with a wheel-in shower, 36 inch doorways, and large spaces sufficient for turning a wheelchair in every room. Since they have lived there, George has come to rely on a mechanical lift for transfers and is currently in the process of applying for a power wheelchair from a provincial government program.

Jane

I met Jane at her office where she works for an organization that acts as a resource for people with paraplegia. She has recently accepted a full time position there, which means she will take a break from her studies at the local university. Jane has paraplegia. A young, attractive woman in her 20's, she reports a changed perspective since her spinal cord injury at the age of 19.

Jane lives in a bungalow, a typical student-type home with several roommates. She says it's not ideal but she's worked out most of the kinks and is managing quite well. Her challenges include the basement laundry facilities, the ramp at the back of the house, and the kitchen and bathroom, which are not spacious enough for turning her wheelchair.

Jane's strong upper body is an asset when environmental barriers do not permit the use of her wheelchair. She has to "bum" down and back up the stairs with her laundry and occasionally will ask for assistance from her boyfriend or roommates to avoid too many trips. The ramp at the back entrance presents a challenge because it is quite steep and there is not a large enough platform at the top. When carrying a load, she is unable to take her hand off the wheel of her wheelchair in order to open the door for fear of rolling back down.

In the kitchen and bathroom she is prevented from orienting herself to face the counter or sink by the typical bank of low cupboards. Though she enjoys cooking, it is difficult due to the height of the stove.

Jane identified the fact that she can access the main floor living area as well as all the bedrooms as a major plus in her current home. She reports enjoying the freedom to visit her roommates in their respective bedrooms in addition to the common areas on the

main floor. On the other hand, Jane reveals feelings of frustration and exclusion when her roommates and friends gather in the basement living room, unaware that she is upstairs.

Michael

I arrived at Michael's apartment building in the dark. It was the third building I had checked as the address was not clearly marked. When I finally found his name on the key pad I pushed it and was surprised to immediately receive the 'buzz' that unlocks the door to let me in, no questions asked. I was greeted by a young woman with a heavy accent (participant's live-in caregiver), who directed me to Michael's bedroom. There he lay prone on the floor, propped up on his elbows, reading a book. He says that this position is most comfortable and functional for him.

Michael is a 34 year old man with spastic cerebral palsy which has left him with little function in his limbs and poor trunk control. He is able to effectively bear weight on his elbows in the prone position, perform one finger typing and control a power wheelchair with an adapted joystick. Michael has struggled with anxiety over the past 15 years and now manages it with medication and counselling.

Many of Michael's complaints about his current residence have to do with security. His apartment was advertised as "handicap accessible" and does have a level entry but fails to meet many of Michael's needs. Michael may be left alone at times for up to four hours, most of that time he spends in the prone position on the floor of his bedroom or in bed which is a low mattress on the floor. The buzzer to let people in the door is located high on the wall outside his bedroom and is unusable to him. His caregiver is able to activate the buzzer when she is there but the intercom feature is broken, so they are unable to identify the person buzzing.

Michael is forced to leave one entrance unlocked when he is alone so that others can enter his apartment if need be. A buzzer attached to the telephone would remedy this problem and is a common feature in apartments. When asked what effect his lack of control has, Michael replied:

Michael: Have you ever had a flat tire in the middle of nowhere? In the middle of the night, dirt road, no street lights, no nothing? Get out of your car, tire's flat, reach for your cell phone and the battery is dead. Go back to the car, fumble around in the dark, open up the trunk, and discover that your spare is flat too. How would you feel in that situation?

Researcher: Scared, helpless.

Michael: Mm-hmm. So pretty much that is what I think anybody can feel. Even in the privacy of their own home, even here...

Other "frustrations" with the apartment's physical design include a hallway with several tight turns, a small bathroom in which a bulky lift is used for transfers and a small kitchen that lacks the space for turning a wheelchair. Michael's activities are therefore limited mainly to his bedroom where his care is provided by his live-in caregiver.

Joe

The interview with Joe had been scheduled over the phone a week earlier. I arrived at the pleasant looking bungalow of the address he supplied me and rang the doorbell at the agreed upon time. Joe's wife answered the door and looked rather confused when I announced my name and purpose for being there. She said that Joe had not mentioned anything and probably forgot. She tried to call him on his cell phone but

was unable to reach him. I said I would hang around town for a while and asked that he or she call my cell phone if the interview could proceed.

Shortly after I left I received a phone call from Joe. He apologized that he had forgotten the interview and said he could still meet that afternoon but would have to wait for someone to carry him up the stairs as he was doing some electrical work in a house for which he was the general contractor. He thought he may have to wait up to an hour for someone to come and assist him and the meeting was rescheduled.

Joe is a 49 year old man who sustained a spinal cord injury at the age of 31 resulting in paraplegia. He was injured while on the job and therefore received a settlement from the Workers Compensation Board with ongoing compensation. Joe used his settlement to build a wheelchair accessible home, which he designed with help from some friends, one of whom had some prior knowledge of building wheelchair accessible structures. He spoke of the relative nonexistence of accessible homes in his town, identifying a need to build with accessibility in mind, especially in light of the aging baby-boomers.

From the outside there was nothing about the house that would identify it as “wheelchair accessible.” Throughout the interview Joe explained the features of the house that were designed to accommodate his wheelchair. Things such as a level entry with low profile thresholds, 36 inch doorways, a wider than normal hallway, a wheel-under counter-top stove, and a section of lowered counter top were incorporated without looking different or odd.

Joe has a keen interest in home design and construction for many reasons. Following his spinal cord injury, Joe went to college to complete a diploma in design and

drafting. He had worked in construction prior to his accident and had enjoyed general contracting. Currently, he continues his work designing and drafting homes and likes to do the general contracting when he can. He reports staying busy enough that he occasionally has to turn down jobs and is very active in his community as a volunteer. Despite being a valuable resource for people with mobility impairments that are designing homes, he does not advertise or promote that skill. He reports that any universally designed homes he has done were for non-mobility impaired people who had been in his home and liked the basic design.

Joe is concerned with his ability to function in the future. He has been diagnosed with rheumatoid arthritis in recent years and suffers from occasional flare-ups that significantly affect his ability to transfer, among other things. With fairly rapid functional decline a possibility, Joe is prepared with a ceiling track lift installed in his bedroom.

Currently, Joe enjoys a high level of independence in his home which he feels also affords his wife more freedom. The day of our second interview she had just left for a week to visit her mother, something that would not have been possible if they lived in a typically designed home.

Ted

Ted is an 86 year old man who uses a power wheelchair for mobility. He and his wife live in a bungalow, close to the centre of town in a small, but growing community. Once again the home has no features that identify it as “accessible” at first glance but it contains all the necessary features to allow Ted to function to his potential.

Ted identifies transportation as a major problem as he is unable to transfer into a vehicle. He travels downtown with his power wheelchair when weather permits and can

use the handi-bus for local trips but has no way of traveling to the nearest city as the handi-bus does not extend past the town limits.

Ted designed his house with the knowledge that he had a deteriorating condition for which he already required a wheelchair. On top of his existing condition, Ted had a stroke a few years ago followed by a below knee amputation which further impaired his function. His decreased ability to transfer necessitated some additional equipment such as a ceiling track lift but no changes to the house, beyond installing the lift, were necessary because of its design.

Cindy

Cindy is a 38 year old mother of three who lives with her husband and children in a bungalow style house in a small town where she owns and operates a small business. Cindy has incomplete quadriplegia resulting from a car accident at the age of 32. At that time she and her family lived out of town on a farm. She had received a lump sum of money as a settlement following her accident and that was used for the purchase of equipment, and for renovating their house on the farm.

After five years in that house, Cindy and her husband made the decision to move into town. They employed a local building company to design and build the house but used their own experience and expertise to make it usable for everyone. Features incorporated to accommodate her needs were: large, open common areas, an ensuite bathroom with wheel-in shower, wider hallway and doorways, a ramp to the front door and an elevator between the main floor and the basement where the childrens' bedrooms are located. Cindy chose not to adapt the kitchen for wheelchair use, as she was happy to relinquish the role of cook.

Cindy reports the move to town as improving her productive and leisure activities significantly. She uses a power wheelchair for mobility and is able to go downtown with her kids or visit others independently when weather permits.

Clair

Clair is a 25 year old student at a local community college who lives with her parents in a bungalow in the city. She has a congenital, progressive neurological disorder which has left her with no lower extremity function and limited use of her upper extremities. She uses a power wheelchair for mobility.

She is able to move throughout the home with her wheelchair with the exception of a sunken living room that she is unable to access. Presently she receives assistance from her parents for self-care activities and reports some difficulty with bathing. She identified a desire to move out on her own in the future. She is aware that she would require assistance from a caregiver but looks forward to this step as a symbol of independence.

Anita

Anita is a 43 year old woman with a long medical history marked by a congenital condition causing deafness and albinism, and by several traumatic injuries. She has decreased upper and lower extremity function requiring use of a power wheelchair for mobility. Anita and her husband live in a newly purchased home which, at the time, was the best they could find with regard to wheelchair accessibility. It is a one story, open concept house in a convenient location, close to a park for her grandsons' enjoyment. She requires assistance from her husband for most self-care tasks. Her husband also has

physical impairments from muscular dystrophy but maintains a fairly high level of function despite its effects and continues to ambulate safely.

Anita's home presents many challenges. Transfers into the shower are difficult and unsafe, doorways are just wide enough to squeeze through and the kitchen is difficult to use due to the counter height coupled with Anita's limited range of motion and strength in her upper extremities.

Greg

Greg is an energetic young man who lives with his wife in a mobile home outside of town. He was injured in a motorcycle accident three years ago and is now paraplegic. Greg enjoys an active lifestyle. He is employed in the oilfield, is active in the church, a member of a wheelchair basketball team and maintains his acreage.

Greg accessed a government program that gave him \$5000 toward renovations to his home in order to make it wheelchair accessible. He added a deck with a ramp onto the front of his house, widened the entrance doorway and expanded the mud room at the same entrance. In order to access the ensuite bathroom in his wheelchair, Greg has had to remove the door and is currently working on installing a sink that he can wheel up to. Greg has good upper extremity strength and is physically fit which is advantageous in overcoming barriers in the environment. He easily performs independent transfers to and from his wheelchair.

Themes

In order to create a snapshot of people with mobility impairments living in homes with varying degrees of accessibility, the experience was framed using three thematic

statements: Doing my thing; Being myself; and Evolving with my environment. These themes are further broken down into topics which will be addressed below.

Doing my Thing

The *Doing* by the participants required compensating for a physical impairment using equipment, assistance or alternative techniques. Accommodating these methods of compensation involved the physical design of the home. Occupation is considered next and is divided into activities concerning self-care, productivity and leisure.

Compensation and accommodation. Much of what we do as human beings requires mobility. When a person encounters a mobility impairment, whether it is due to a congenital condition, trauma or disease, he or she can use compensatory techniques and/or devices to restore mobility. Something consistent across all participants in this study was their use of a wheelchair as their primary means of compensating for their mobility impairment. While wheelchairs were the most visible tool, participants used additional equipment including bath lifts, mechanical lifts and wheelchair lifts to assist with mobility.

The wheelchair is a very effective aid in some environments however, it can quickly become unusable in others. While participants usually tried to steer clear of environments where there were known barriers, at times they were unavoidable. The use of alternative compensatory techniques such as, crawling, shuffling, “bumming” (use of their upper extremities and trunk in sitting position) and assistance from others was then necessary in order to mobilize. These methods of mobility generally take much greater effort and draw attention to the person using them. Jane described feeling “different” when unable to access a bathroom with her wheelchair:

The only time I ever feel out of place or awkward is when, if I go somewhere and I need help to get into a washroom or I try and get in and I can't fit and then you feel out of place where as if you just went somewhere and you can just do your thing and come out then it's, yeah, you don't feel like you're different from everyone else.

To allow participants to function effectively, the environment must be able to accommodate a wheelchair and the user who is now at a height not typically considered in home design. Things such as level entries, door and hallway width and counter top height become of major importance to the completion of tasks within the home. Jane finds cooking somewhat dangerous because of the height she is at in her wheelchair, "I've had times when I've been frying bacon, anytime I fry stuff, when it spits it gets me in the face." Bathroom design was commonly an area of concern. Anita relays the process of trying to have a shower in her typically designed tub/shower set up:

The problem is I can't lift my legs, so now what we have to do is stand and hold the wall, lift the leg this way, and [husband] then puts it in. And then the other one and then he puts it in, and then I move across the wall and then sit down...which is more dangerous.

At the suggestion of a wheel-in shower, Anita replies, "Yeah, a whole lot safer and I think that if it was – the set up idea that I have, I think I could manage just about everything myself."

The design of the home affects the degree of assistance required to perform occupations. According to the Canadian Model of Occupational Performance, human

occupation, or what “occupies” us, can be described as consisting of activities related to self-care, productivity, or leisure (CAOT, 1997).

Self-care. The ability to care for oneself or be cared for in an efficient manner seemed paramount for these participants and allowed them to spend their energy in other, often more fulfilling areas. Joe recalls his time shortly after his spinal cord injury when he lived with a friend while his wheelchair accessible house was being built:

I couldn't dream of going back to something like that...I wasn't doing nothing then, that first year. I wasn't even - I didn't have a job, I wasn't going to school yet ...basically...it took all day just to live.

Of the three categories of human occupation, self-care seemed to stand out as almost a prerequisite to productivity and leisure.

Productivity. Many of the participants, including Joe, are vibrant, active members of their communities. They contribute through involvement in learning, advocacy, and volunteer and paid employment. Though many receive Alberta Income for the Severely Handicapped (AISH) or Workers Compensation, they often pursue different vocations in an effort to fulfill their productive roles, whether paid or unpaid. George maintains a useful role in the family ranch. Though progression of his disease has kept him home more often, he is able to complete his tasks using the computer and telephone. It is one area in his life where he still feels effective.

I'm still able to do all the paperwork for the cattle...I do the farm accounting and I'm the gopher. If someone needs something or is trying to find something I get to do all the phoning and that sort of stuff.

Greg continues with the yard maintenance on his acreage in addition to his paid employment and leisure pursuits, something he did not consider when he was renovating his mobile home. When asked if there was anything he would do differently now, he replied, "I might have made the ramp wider so I could have drove right up here with the lawn tractor."

Cindy, who runs a retail outlet, describes her decision to move from the farm into town and start a small business,

I was getting bored and depressed because...that's when we lived on the farm and nobody, you know everybody had jobs or had families, so nobody would come to visit. I found myself coming into town almost every day, just doing nothing, spending money, buying stupid things. So I said to [husband], you know this business came up, so I said to him [youngest daughter] is going to be in school and I'm not sitting at home by myself watching TV.

In the past Anita had enjoyed beading and leather work, activities she would like to resume. Feelings of depression had replaced her motivation to create, "I got into a real bad depression there for a while where I didn't do anything. I was so distraught and angry with the world that I just gave up."

Leisure. Leisure pursuits among participants varied, but much of the time were centred around activities in the home. While active in the community as a general contractor and member on several volunteer boards, Joe prefers to spend his leisure time at home, "me and [wife] would rather stay home and watch a movie...it's comfortable. And especially me being in a wheelchair, it's more comfortable for me being [here], than being anywhere else really." Likewise, Jane prefers to socialize at home:

I like having people come to my house rather than me going to theirs, like to entertain or socialize, because I don't know if the bathroom is upstairs or downstairs or...So I guess where I'm living now, it's comfortable to be there cause I know I can do everything, like there's obstacles but I've worked through them.

It was common for the participants to report calling ahead or asking friends about the 'accessibility' of certain built environments before visiting places in the community. Of greatest importance were stairs and bathrooms. When asked if she calls ahead when she is going to a new place, Jane replied, "Bathrooms are a huge one for me. Like I'll always ask someone, if they've been there, what's the bathroom like? Is it big, can I get in, is it on the main floor? Oh, and stairs too."

Where the ability for physical compensation (i.e., upper extremity strength) existed, there were very few barriers that could not be overcome. When asked if he visits friends and family Greg replied, "Yeah. There's usually someone there to help me if there's stairs, or I can drag myself up the stairs. They can bring the chair and I jump on the chair." But some participants considered whether the enjoyment they would get from the activity or social interaction would be worth the extra energy necessary to get there. Jane described a scenario,

Sometimes I'll come home and all the roommates are downstairs and I can hear them all down there just hanging out, like in the downstairs living room.

Sometimes they just hang out down there if that's where people start off. And then it's like, like I would go down there but sometimes I just don't cause it's a

bother to...I don't know whether they're gonna come up or whether it's worth it to go down.

Where their roles in life were many and full, their self-care needs, it seemed, were generally met in an efficient manner. Where the home environment was less conducive to self-care, other areas seemed to be less well developed. Anita conveys feelings of frustration around her social and leisure pursuits, "Sometimes I go out for coffee in the afternoon with my daughter and my grandsons, my husband, but I don't do anything! Basically I'm a TV fanatic." Michael, who is taking a break from his studies at a local university and is currently between jobs admits his social life is somewhat lacking.

I can't usually have visitors in on the spur of the moment. If we forget to leave the glass door open they can't get it. Not being able to move around as readily as I would like for whatever reason means that my visitors have to do a lot for themselves. I can't offer to get someone a drink. They have to get it themselves. They may have to get me one. The hospitality thing suffers, not that I do much entertaining anyway, but it would be nice to have the option.

Being Myself

The theme *Being myself* led to the discussion of roles and thoughts on being disabled. The meaning of independence and the meaning of home for participants is considered as well.

Fulfilling roles. It is the roles we acquire that define who we are. We are mothers, husbands, carpenters, secretaries, members of the church, students. We gain satisfaction from these roles and draw meaning from the process of fulfilling them. When the challenge of caring for oneself or being cared for is all consuming, one's roles diminish

or decrease because of lack of time or energy. Occasionally, physical impairment and/or obstacles in the environment make fulfillment of a role too difficult so it is given up. The negative effect of having to give up an activity that fulfills a role is evident in Anita's statement:

Cause I love to cook and bake and stuff, I miss it. I miss cooking for [husband].

When I used to see him sit down to a good meal and devour it, that I had cooked, that made me feel good, like I had accomplished something, you know. Now he does all the cooking.

Following changes in physical abilities, roles are often modified and adjustments are made within the family to accommodate this. In some cases roles are dropped as in Cindy relinquishing her role in the family as cook. Conversely, Joe has expanded his domestic role. He states, "I do most of the cooking. She [wife] works so, a lot of time if I'm around I'll do the dishes...all the drawers and cupboards can pull out so I don't have to reach way back."

On being disabled. When asked about their thoughts on disability, the most remarkable and common answer was that they had not really thought of it. Joe responds:

I don't know, I never say one way or another. I mean, you can see I'm in a wheelchair...I guess there isn't much that I don't do...But when I think of myself, I definitely know that I have a disability because I'm paraplegic but I am not scared to try anything...and most things I can usually find a way to do.

There seemed to be a distinction, once pondered for a moment, between feeling disabled and being seen as disabled. Most of the participants did not feel disabled but thought that others saw them as such. As Jane says, "I don't ever think about that [being

disabled] because I don't feel like I am...but to the public I would be." George shared the same view and along with Greg saw disability as more of a mindset, viewing attitude as the disabling factor. When asked if he considered himself disabled, Greg explains, "I try not to think of it that way, before I do that I'll try and find a way to get done what I'm trying to get done."

For the most part, participants had grown accustomed to other people's reactions to their impairments, but could recall a time when they were bothered by it. Jane shared a story about an incident where a person's misconceptions were voiced, "I went to a store once and as I was passing a girl in the doorway and it was kind of awkward and then under her breath she was like, *wow you're really pretty for someone in a wheelchair.*"

Michael offered an interesting theory regarding peoples' fear and uncertainty around someone in a wheelchair:

People see the wheelchair and they don't see me. But they don't really see the wheelchair either. All they see is what could be and what probably will be. And it's all symbolized in this chair that happens to have four wheels on it. And in many ways, I mean, I hate to give away the big secret here but as you get older you may find yourself, in one aspect of your life at least, similar to an aspect of my life. It can be something as simple as using a cane to walk or having to rely on someone for a time to help you with your physical needs. And people find that, I think, intimidating because it's the same as...seniors who have found the prospect of losing their drivers license frightening and offensive and they become enraged by it. And why is that? Because that is a symbol of their independence and it's slipping away. And when people see the wheelchair they see the same thing: the

independence slipping away. Am I completely independent? No. But am I completely dependent? No. But people – unless they have had dealings with disabled people, unless they know disabled people they don't know that. So it's the culmination of all their fears wrapped up in this package.

With regard to the environment's role in disability, participants acknowledged it as having an enormous impact but generally did not view it as the sole causal factor. When asked if she thought disability is caused by the environment, Jane replied, "no I think the environment makes you aware of it but like I think even if I'm in a healthy environment I'm still someone with a disability."

Meaning of independence. Independence, something most of us take for granted in our adult lives, hangs in a delicate balance for many faced with physical impairments. Receiving assistance from others has numerous effects on both the giver and receiver of assistance. Interpersonal relationships are occasionally tested while a family adjusts its roles following a significant change in one member's physical abilities. Anita describes the change in her relationship with her husband and the value she places on independence:

To be able to shower by myself would be like being able to walk again...that huge of a difference in my life. I really hate relying on other people for everything. Like right now I can't get into the kitchen and it annoys the living daylights out of me. I can't make myself a cup of tea. I got to – it's like he's my servant instead of my husband, you know?

Despite these challenges, many of the participants reported that receiving personal assistance from homecare or agency workers wasted too much time and left them feeling

out of control. The convenience of having a spouse provide personal care outweighed any detrimental effect on the relationship. Cindy illustrates this in this passage referring to assistance received from homecare:

I mean, they have come and haven't been able to put a catheter in...and sat there for forty five minutes and then [husband] does it in two minutes...So that's just easier to have him do it...he doesn't mind, we have talked about it.

It seems when the participants felt they were maximizing their potential, accepting help now and then did not bother them, as Joe describes,

Sometimes I've even had people be walking by and if they see that, if it looks like I'm having trouble then a lot of people will ask and give me a hand, and if – I don't have a problem saying sure...then they'll usually give you a hand to get in and I'll say thanks.

Maximizing occupational performance within the home also appeared to have an effect on the meaning of home for the participants though several contributing factors were identified.

Meaning of home. The meaning of home for people in this study was multi-dimensional and was affected, in large part, by life stage, financial status, and functional design. Three of the participants were younger or at a stage in life where people do not typically own their own home. Each of these three saw their home as temporary. Jane described it as “more just where my stuff is and where I go to just be comfortable and relax.” Michael states his reason for being in his current home as proximity to the university, bank and stores and is clear about his intentions once this proximity is no longer necessary. “If I'm still here in ten years please come back, bring a gun and shoot

me...if I'm not in university, I'm not staying here." Michael's experience of his home is basically restricted to his bedroom and bathroom as he reveals here:

Getting in and out of the kitchen would be a problem. And I don't really have a good feel for where things are in the kitchen, and that's partly my fault. I can have a better idea; I should go out there more often. I'm very concerned with what goes on in here [bedroom] because I'm involved in here, but not out there so much."

Clair found her home "comfortable" but identified a goal of moving out on her own.

Owning a home seems to carry with it a dimension of meaning that is independent of its functionality. Anita, for example, identified that while the design of her home was not perfect, it did provide "...stability cause it's ours. You can put a nail where you want," as opposed to renting. Michael attached these meanings to the prospect of owning his own home, "It's a sign of independence, it's a sign of freedom, and it's a sign of achievement."

Where participants owned their homes and functioned efficiently in them, the meanings they ascribed to them seemed to echo those of the general population. Words such as security, privacy, and comfort were used by these participants to convey meaning in relation to their homes. Additionally, there was a freedom of movement and activity described that could not be taken for granted in other environments. This freedom often led to the home becoming the hub for activity as mentioned earlier.

Through transition of life stages, injuries, bodily changes, disease progression, and changing roles, interaction with the environment is a dynamic process. Because a home is a long term structure, it is important to be proactive in choosing or designing a home. 'Making do' with a less than ideal home is often necessary for people with

mobility impairments as was revealed in this study. The availability of universally designed homes and the resources necessary for obtaining them will be considered next, followed by a look to the future and the need for change in society.

Evolving with my Environment

The theme *evolving with my environment* encompasses the journey of making do, getting to their current situation considering housing resources and availability, and looking ahead to future needs and wants. Identifying a need for change at a societal level is also addressed.

Making do. In each case, even where participants now enjoy maximum usability of their homes, they could recall a home environment much less conducive to function. For a variety of reasons such as finances, life stage, recent injury or unavailability of accessible housing, all participants tended to ‘make do’ or compromise function at some point for a roof over their heads. Joe recalls the home he lived in immediately following his spinal cord injury:

It was terrible, but it we made do because that was the only place I had to stay until this [current home] was being built...it was functional but it was tight getting through the doors and the halls were narrow....I mean it wasn't wheelchair accessible but we made it work.

Following Jane's injury she lived with her parents. She described the home as a four level split. "So there's a kitchen and living room [on main floor] but other than that for bathroom or bedrooms you have to do the stairs...bum up and down....it was tough, like I couldn't do anything on my own."

Once the participants had enjoyed the independence afforded by an accessible home environment, returning to environments less suited to their needs caused frustration. Joe recalls his experience of having to stay in a hotel for an extended period while his house underwent repairs after a flood:

It was a pain in the ass over there compared to living in my house, just having a bath and a shower and all that kind of stuff, going to the bathroom, getting on the toilet. I mean, just even brushing your teeth.

Likewise, with regard to the design of the home, Jane reports visiting her parent's home now as "frustrating...because I'm used to being independent."

Availability. For Anita and her husband, once the financial hurdle of purchasing a house was overcome, availability prevented them from choosing an accessible or universally designed home. Anita describes their move to purchase their current home:

Anita: So I went to a – there was a guy that was recommended to us, a realtor, and I said, I just laid it on the line and I said, and I need it now [laughter]. And I made him work for us.

Researcher: Did you outline your needs as far as accessibility?

Anita: Yes, and he really did find the best that he had... And it can be with not as much work – it's a one-level, you know, everything is fairly open; it's an open concept house. It's an old house though so the doorways are a little narrow. But there are not a lot of doorways so we're looking at the bathroom door and the bedroom doors basically, and the front door. So that's what we're looking at for doorwise...to enlarge.

Throughout the interview Anita goes on to describe the inaccessibility of her kitchen and bathroom and the difficulty she has with self-care tasks.

The homes of Michael and Jane are also “the best they could find,” given their requirements, though not ideal. Joe comments on the need for and availability of universally designed homes: “Now, like for seniors, there's the big need for that kind of housing, it's just not around... I've had offers on this one like you wouldn't believe.”

Resources. Currently there are no government programs in this area to assist financially with building a universally designed home. There are a couple of programs to assist with renovations however; The Residential Access Modification Program (RAMP), funded by the provincial government (Alberta Seniors and Community Supports, online document retrieved July 2, 2008) and a federally run program called Residential Rehabilitation Assistance Program (RRAP) (CMHC, 2005). Cindy and Greg had each accessed one of these programs for renovations and Anita plans to in the future. As Anita's husband points out, however, they are not well known, “Unless you're working fluently with an OT [occupational therapist] or somebody like that, you don't find out about any of these programs.”

When finances allowed and a decision to build or renovate was made, resources for building accessible or universally designed homes were scarce. Most participants who built new or renovated reported using their own design to make the home accessible. George, on the other hand, recalls his experience of having an architect draw up his house plans:

George: Well we made a big, big mistake. We went to a, supposedly, an architect in Lethbridge who was supposedly the up and coming, the guy that designs for handicapped people and stuff. And that was a complete and utter waste of money.

Wife: He had several really drastic mistakes. If it hadn't been for our contractor...

Looking ahead. Of those participants who are currently “making do” in less than perfect environments, all have their ideal house in mind. Most of them have stayed, at one time or another, in different environments that presented fewer barriers than their own home such as hotels, condos and, in one case, a teepee. Through experience with various environments they have become experts with regard to their environmental needs. While universal design is the base for all of the ideal homes, each individual has different requirements for specialized design based on their roles and abilities. Michael, for example, has conceived of a home that is not only wheelchair accessible but contains various technological aids and environmental controls. Jane and Anita both desire a fully wheelchair accessible kitchen as they both enjoy cooking. Greg and Ted, on the other hand, were not as concerned with full access to the kitchen in their homes because cooking is primarily part of their wives' roles. Joe had to accommodate both his wife (in standing) and himself (in wheelchair) in the design of his kitchen.

In every case participants identified some area, either in their home or in the community, that if changed would afford them greater independence and greater opportunity. Maximizing independence therefore involves removing environmental barriers. While accommodating wheelchairs improves accessibility for many, it is not the only means of compensation used by people with mobility impairments. The difference

among people with mobility impairments must be taken into account. Michael recognizes this diversity in this statement,

The ideal that I think we should shoot for with regard to building design or residence design, if you will, is if you build a residence or a complex that is as adaptable as possible, if you build a space that can be modified as much as possible to accommodate this person, and then the next person, and then the next person after that then you've achieved what I think would be a good place to be. That is the goal that we should shoot for. When you have a space that has stairs and doorways that are very, very thin and everything else...the space is not easily adaptable.

Aging and disease progression add yet another variable. People's abilities change over time and must be taken into consideration in the design of a home. Both Ted and George have gone from independent transfers to assisted transfers to mechanical transfers throughout the progression of their diseases and aging. George also faces a change to a power wheelchair in the near future to restore independent mobility in his home. When Joe was experiencing an exacerbation of symptoms with rheumatoid arthritis, a ceiling track lift was installed. Though he currently does not have to use it, he recognizes the likelihood of its eventual necessity. All of these equipment changes were easily accommodated within the homes, a credit to their initial design.

A need for change. From conducting surveys to sitting on volunteer boards to working as an advocate for people with mobility impairments to participating in this study, all of the participants have contributed to the knowledge base with regard to the built environment. Their experience has made them a valuable resource for those who

find themselves in a wheelchair for the first time or those who are designing a home for long-term use. Most of the participants highlight the increasing need for universally designed homes in light of the aging population. In speaking about the possibility of governments offering incentives to build universally designed homes, Michael replied, “Well they’re going to have to do something because we’re going to be facing a real challenge when the baby boomers really start retiring.” In reference to building a universally designed home, Ted concluded by saying, “As I’ve said before, I would recommend it to anybody 45 or older who is going to build a new house, to think of the future. They may never need it but you never know either.”

Summary

Following the introductions of the nine participants ‘in context’, the themes doing my thing, being myself, and evolving with my environment were presented. Excerpts from the participants’ transcripts were used to exemplify each theme and provide an experiential description to support them. Several conclusions were drawn from the data and are presented here following their corresponding theme.

Doing my thing: 1. Compensation for mobility impairment must be coupled with the environment’s capacity to accommodate that method of compensation for efficient performance of occupations. 2. Safe and efficient performance of self-care activities appeared to coincide with participation in a wider range of occupations (i.e., activities related to productivity and leisure).

Being myself: 1. Loss of roles due to impairment effects and environmental barriers were linked to feelings of depression. 2. Participants generally did not think of themselves as disabled but thought they were perceived by others as such. 3. Receiving

assistance from others was shown to be less frustrating when participants felt they were reaching their potential for independence in the home. 4. Where homes supported occupational performance in this study, the meanings that participants ascribed to their homes were similar to those of the general population (Despres, 1991).

Evolving with my environment: 1. Each participant was forced to ‘make do’ with a less than ideal home environment at some point due to finances, life stage, recent injury, and/or availability of appropriate housing. 2. There is a lack of universally designed homes on the market. 3. Resources for building or renovating for accessibility are not well known. 4. Participants recognize the need for a change in the typical home design on a societal level. The following chapter will address these conclusions in the context of the existing literature.

Chapter 5

Discussion

Situating this data within the existing research offers support for the findings but also highlights areas of future investigation. Though admittedly a preliminary look at the effect of the built environment on people with mobility impairments, this study illuminates the ever increasing need for a change in the typical home design. The pivotal role the environment plays in the lives of the participants is brought forth repeatedly in the telling of their stories. Following the thematic format of chapter 4, an attempt will be made to relate the current finding to those in the published research. Limitations of the study will then be discussed followed by recommendations for future research, implications, and concluding remarks.

Doing my Thing

Support for the findings was present in several documents reviewed for this research. The topics Compensation and Accommodation and Self-care, Productivity and Leisure are considered below.

Compensation and Accommodation

In order to achieve function, the need to compensate for the impairment of mobility must be coupled with the environment's ability to accommodate that method of compensation. Of those participants in this study living in less than ideal environments, changes to their home environments would result in greater independence in every case. It is estimated that, "over 70% of adults with disabilities in Canada need help with everyday activities, such as dressing, eating, taking care of personal hygiene and getting around" (Office for Disability Issues, 2004, p. 17). While the severity of the impairment

has an effect on the potential for independence, one should not overlook innovation and creativity as vehicles for improved function. Examples of participants' creativity were endless when it came to overcoming barriers. Michael said:

As much as we try we will always be subject to the environment...the environment shapes our lives to a very great extent. Having said that, you know, at the same time I would make the argument that we are only limited by our innovation. We can come up with different ways of doing things.

This attitude, so common in the interviews, is supported by Gitlin's (2003) personal control theory and Imrie's (2004) observations that disabled people tend to be proactive and resourceful in overcoming barriers imposed by society and specifically the built world.

Self-care, Productivity and Leisure

According to the findings of this study, efficient performance of self-care activities, whether assisted or not, appeared to provide a foundation from which to expand the occupational lives of the participants. The ability to perform self-care activities efficiently was largely the result of the home's capacity to accommodate any necessary equipment. This phenomenon is supported by Lawton and Nahemow's (1973) Environmental Press Model and can be conceptualized using the river metaphor of the Kawa Model. In accordance with this metaphor, the unimpeded flow of the river represents the usability of the home environment. Where barriers in the home exist, one can imagine the flow of the river (the space allowing the performance of occupation) encountering resistance. The resistance is caused by obstructions to flow due to

narrowing of the river's banks (e.g., stairs in the home) which is easily compounded by rocks (e.g., paraplegia) and driftwood (e.g., use of wheelchair for mobility).

Being Myself

Several topics addressed below receive support from the literature. Thoughts *on being disabled*, however, reveal ideas not addressed in the literature reviewed for this study.

Fulfilling Roles

Adjustment to changing roles following an injury or progression of disease was significant to participants. Linking depression in disabled people to the loss of roles is seen throughout the literature (Gitlin et al., 2001; Heywood, 2004) and was evident in this study.

On Being Disabled

The discourse on disability models in the literature is primarily the product of academia. The social model of disability, however, was derived from the social relational understanding of disability, which was a product of the consumer driven disability rights movement (Barnes, 1997; Thomas, C., 2004). It was assumed, therefore, that the social model would largely represent the views of disabled people themselves. It was surprising to discover that, indeed, it did not. Many of the participants regarded themselves theoretically as disabled regardless of the environment, though most reported not “feeling” disabled. Interestingly, their initial, pre-reflective response was that they do not ever think about it and held quite a perplexed expression when asked. As phenomenology strives to gain insight through pre-reflective thought (van Manen, 1990), perhaps the initial reaction is more telling than their reflective, theoretical stance which could be the

effect of their upbringing with the predominant medical model. They also made a distinction between the way they felt and the way society viewed them, an indication of an awareness of stigma as outlined by Barnes (1997).

Meaning of Independence

The high degree of importance that participants placed on independence is congruent with Heywood's 2004 study regarding understanding the needs of disabled people and Gitlin's (2003) belief that personal autonomy and control are two important contributors to well being.

Meaning of Home

Imrie's (2004) study suggested that themes gleaned from mainstream literature on the meaning of home were not representative of the meanings held by disabled people. This was consistent with the findings of this study only when the home environment was not conducive to function. Where homes supported occupational performance in this study, the meanings that participants ascribed to their homes were similar to those of the general population (Despres, 1991), again supporting the social model of disability.

Evolving with my Environment

The topics *making do*, *availability*, *resources*, and *looking ahead* are considered next. Relating the information from these topics to the research reviewed for this study provides` support for the findings.

Making Do

In this study, finances, life stage, recent injury, and availability of appropriate housing were factors contributing to participants living in homes with environmental barriers. Lack of finances is often mentioned in the literature as being associated with

environmental barriers (Gitlin et al., 2001; Mathieson et al., 2002). Life stage and recent injury were not addressed in the literature reviewed in this study, however they may have an effect on financial stability.

Availability

Participants in this study who chose to buy or rent an existing home had to make do with the best they could find, putting up with inconveniences and compromising safety, in some cases, because of a lack of accessible or universally designed homes on the market. Availability of universally designed homes in this geographical area was difficult to ascertain, as no central registry exists, but personal experience in the market and participant reports indicate a relative nonexistence. The CCDS (2007) identifies “a lack of housing stock that even has basic access in Canada.” Universal design and accessibility are not marketable features traditionally. Michael offers an interesting view on the subject:

It’s going to become a growth industry. People like me are actually going to become marketable. Wow! Which has not been the view historically.

Accommodations have been seen as an expense, not an attraction. It’s not attractive to be disabled; it’s not attractive to have a medical impairment or a medical condition where you need these types of things. But now that we have so many people on the cusp of retirement and all of the conditions and problems that come with aging, many of which ironically at 34 I already have as a result of my disability, these features are going to become attractive. Great, wonderful for people like me. But it is going to be a real problem for society as a whole because as good as we think we are there’s a lot of catching up to do.

Resources

With the exception of one, participants who had designed or renovated their homes to be wheelchair accessible found resources scarce. They took on the role of expert in the design of their home to enable performance of occupations. Viewing the client as expert in their own needs is part of the client centred approach to occupational therapy (CAOT, 1997). Their experience of their own bodies in relation to the environment is invaluable for shaping their ideal home.

There is an ever increasing amount of technical information available on the Internet and in print with regard to universal design and visitability (CMHC; Concrete Change; Center for Inclusive Design and Environmental Access; Center for Universal Design, NCSU). There was no knowledge of these resources within the study sample. A lack of knowledge was also identified in the housing industry in the CCDS's (2007) survey on visitable housing in Canada. The task remains to inform consumers, occupational therapists and people in the housing industry about existing resources.

Looking Ahead

While the ideal home for one person looks different from that of the next, the basic features of universal design is a starting point for all, as seen in this study. This reflects the first two principals of universal design, which are equitable use and flexibility in use. This means the design is “useful and marketable to people with diverse abilities” and “accommodates a wide range of individual preferences” (Connell et al., 1997). These principals were recognized by Jim Sandhu in his 2004 opening keynote address for *Designing the 21st Century III: An International Conference on Universal Design*,

“Universal Design not only provides a framework for action but is an approach that values and celebrates human diversity” (p.1).

The participants of this study recognized the need for changes in the way homes are typically designed. Incorporation of universal design concepts in all newly built homes would begin to address the housing crisis that will inevitably result from the increased proportion of people with disabilities as the baby-boomers age.

Limitations of the Study

With the exception of one aboriginal participant, the study sample represented one predominant cultural group (Canadians of European descent). Culture has been shown to influence the meanings people ascribe to concepts such as independence (Iwama, 2006), and may have an impact on the way in which the home environment is experienced. The participants were also from the same geographical area. This meant they were subject to the same government programs and resources with regard to building or renovating for the purpose of improving the accessibility of their homes. Finally, the participants were referred by either a community occupational therapist or the Canadian Paraplegic Association which indicates a connection to services. These similarities create a more homogenous study sample which may affect the extent to which the findings can be generalized.

Future Research

The interdependent relationship of the person, environment and occupation was evident throughout this study. An investigation targeting, more specifically, the occupations of people with mobility impairments in relation to their home environment would produce interesting results. Linking these results to quality of life and well-being

would also be insightful. Quantitative data may be useful in examining the frequency of hospital, lodge and assisted living admissions relative to the design of the home environment and may have an impact on policy. Lastly, the participants' description of not feeling disabled while believing they are perceived by others as such, provides a springboard for future inquiry.

Implications of the Study

Throughout the planning and performing of this research and its written presentation, there has been an underlying emancipatory agenda. Being sensitive to the 'participant as expert' in disability research (Hammell, 2007b; Stone & Priestly, 1996), disabled people are invited to draw their own conclusions from the presented findings. The data itself, without this researcher's interpretation, illuminates the importance of home design in the occupational lives of these participants. It is with confidence that this thesis is presented, knowing that the underlying goal of promoting universal design to consumers, policy makers, and people in the housing industry was reiterated time and again by the participants themselves. It is through the participants' words and the researcher's interpretations that these people might be enlightened as to the importance of universal home design to the population as a whole.

With a shift to improved design, improved function by people with mobility impairments will have far reaching effects. These effects range from fewer admissions to institutions such as lodges and assisted living facilities to a gradual change in social perception of people with physical impairments. This change would lend credence to the third phase in Finkelstein's materialist analysis of disability. Following the exclusion of people with impairments in the industrial era of the 19th century (phase two), the third

phase involves the “liberation of disabled people from such oppression” (Barnes, 1997, p. 8). The support provided for the social model of disability through this research will contribute to the advancement of human rights for disabled people.

Implications for the occupational therapist include promoting recognition of the client as an expert with regard to his or her environmental needs. For the most part, where participants in this study were financially able, they designed their homes to be as functional as possible with great success. For participants in less functional homes, they had conceived of a design that would improve their occupational performance. Living with and using their bodies, each with its unique method of function, to perform the occupations that are meaningful to them, has given the participants exclusive knowledge of their needs with regard to the environment. The job of the occupational therapist is to provide the necessary resources and contribute knowledge and information to enable the change to, or acquisition of, such environments.

The literature review (Chapter 2) contributes to the knowledge base regarding imposed changes in the home and its intricacies. It is clear from previous research that success of imposed changes to a home depends on many factors. The data from this study show that initial design based on the participants’ wants and needs, and those of his or her family, was conducive to use and function.

Improved knowledge of available resources regarding universal design and related movements may also result from this study. At the very least, it provides a starting point for considering the effect of universal design on people with mobility impairments if not on the population as a whole. By opening dialogue regarding the home

environment and its effect on people with mobility impairments, additional research will continue to improve our knowledge in this area.

From the researcher's perspective, the learning and deeper understanding gained by the process of reviewing the literature, gathering data, and analyzing the participants' words has been remarkable. Coinciding with this intellectual leap has been the ongoing personal experience of being beside a loved one who has exemplified so much of what has been learned through this process of research. Unfortunately, it is only in retrospect that it all begins to make sense. We live and study and write in order to learn and as the researcher, having the personal experience right beside my academic endeavour has certainly enriched my understanding of the phenomenon in question. It is my hope that the implications, beyond those that are personal to me, will be realized.

Conclusion

Building a universally designed home has been shown to maintain a feeling of control, maximize functional potential, and provide opportunity for fulfillment of roles. It is offered that when enabled by the design of the built environment, peoples' occupational lives are richer. To return to the river metaphor of the Kawa Model (Iwama, 2006), they are flowing freely with fewer obstacles, creating a strong "Life Flow". The primary focus of this research was to gain insight into the lived experience of people with mobility impairments in the context of their home environment. The contributions of the social, cultural and institutional elements of the environment (the participants' horizon) are inextricably embedded in the responses of the participants. The interdependent nature of the person-environment-occupation relationship was obvious as well (CAOT, 1997;

Iwama, 2006; Law et al., 1996). Change in any one of the three dimensions affects the other two.

Brought to my attention following the analysis and interpretation phases of this research was the work of A. A. Wilcock. Interestingly, Wilcock (1999) describes occupation in terms of doing, being, and becoming. The similarity between this description and the themes extracted from the current research was cause for contemplation. Though once again grasping for some grand revelation, simplicity prevailed. People experience the environment through occupation. Not a news flash for occupational therapists but a reminder to look to the foundation upon which the profession of occupational therapy is built.

The themes of Doing, Being and Evolving could conceivably be applied to any population in relation to their home environment. Where the barriers in the built environment were greater, the occupations engaged in by the participants were fewer and were often a source of frustration. This provides support for the social model of disability.

Movements such as universal design and visitability have a goal of widespread acceptance and incorporation of at least basic access to homes. Seeing this change in the typical home design would not only provide greater choice in housing for people with mobility impairments but opportunities for social engagement and community involvement, an 'occupational right' (Hammell, 2008).

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Appendix A

List of Universal Design Features

1. Level entry
2. Doorways 32" or wider
3. Walk or wheel-in shower
4. Raised dishwasher
5. Lever handles
6. Main floor laundry facilities

Appendix B

Invitation to Participate

DO YOU:

Live in a home that is designed or modified for use by people with disabilities?

Have a mobility impairment?

Have an interest in contributing to research regarding the effects of the home environment?

I am an occupational therapist performing a research project as part of a Master of Health Science Degree at the University of Lethbridge. The project will explore the experiences of people with mobility impairments who have chosen to live in a house with accessible design features. If you are interested in participating or would like further information, please contact Jill Perry at 345-5262 (collect calls will be accepted), or by e-mail at jill.perry@uleth.ca. Your commitment will involve two interviews in your home, lasting one to two hours. Your interest is greatly appreciated.

Thank you,

Jill Perry, BScOT

Appendix C

Demographic Information

Name: _____ Pseudonym: _____

Age (as of July 1, 01-07-2006): _____ Gender: _____

Educational Status: _____ Marital Status: _____

Occupation: _____ Ethnicity: _____

Address: _____ Phone: _____

Medical history: _____

Diagnosis: _____

How would you describe your health? _____

Estimated yearly gross income: _____

Funding or assistance received for building/renovating: _____

Number of people residing in this home (including you): _____

Their relationship to you: _____

Appendix D

Sample Interview Questions 1

1. Tell me about your living situation prior to this?
2. What made you decide to change your living environment?
3. Tell me about the process of designing this house.
4. Describe the features in this house that specifically suit your needs.
5. Are there any features that limit you?
6. How has the design of this home affected your daily activities?
7. Have you noticed any changes in your leisure activities or social life?
8. Does anyone else live here with you?
9. How does the design affect the others in the house?
10. Can you think of some words that would describe what this home means to you?
11. Would you describe yourself as being 'disabled'?
12. Do you feel you have different levels of disability in different environments?
13. What effect does your home have on your level of disability?
14. Do you believe that 'disability' is caused by your environment or is it something that is within you?
15. Are there any other words you can think of to describe the meaning of this home to you?

Appendix E

Sample Interview Questions 2

1. Tell me about yourself.
2. Tell me about your house.
3. Describe a typical day for you.
4. What do you like about your current house?
5. How does the design affect others in the house?
6. What would you change if you could?
7. What does this home do or provide for you?
8. Can you tell me about the best and worst place you've lived?
9. How did you choose this place?
10. Where would you like to be five or ten years from now?
11. Would that be your ideal living situation?
12. Do you see yourself getting there? If not, why?
13. How does the built environment affect your leisure activities or social life?
14. Do you feel you have different levels of ability in different environments?
15. What role does the environment play in disability?
16. Do you think of yourself as disabled?

Appendix F

Consent to Participate

Research Project Title: Freedom by Design

Researcher: Jill Perry, BScOT

This consent form will give you a basic idea of what this research is about and what you will be asked to do. If you would like more detail feel free to ask. This research is being completed as part of a Master's thesis. Please take the time to read this carefully.

Freedom by Design is a study about people with mobility impairments who have chosen to use accessible design features in their home. It asks what lead to this decision and how an accessible living space has affected the meaning of home for you. There will be one or two interviews that may last from one to two hours. Interviews will take place in your home and will be tape recorded and transcribed. You will be given a copy of the transcript to read.

You have the right to withdraw from the study at any time. Your part in this study is completely voluntary. You will not be paid for your time. Possible benefits to you may include: 1) being able to share with others the effect home design has on someone with a mobility problem. 2) being part of knowledge building about something that may help to improve human rights of people who are disabled.

The researcher will read the transcripts from the first interview and pick out themes about the research topic. You will also be asked to read and discuss these themes. If you and/or the researcher feel another interview would be useful to clarify or expand on these themes, a second interview will be arranged.

Your identity, as part of the study, will be kept confidential. Code names will be used on all transcripts. Tapes and transcripts will be locked in a filing cabinet that only the researcher can open. After you have read the transcripts the tapes will be erased. Transcripts are considered to belong to the researcher and may be quoted in the final writing of the findings. You will not be identified in the findings.

There are no major risks for you being involved in this research. In the rare event you feel emotional distress by telling your story, and are interested in counselling to assist you with this, the researcher will give you names of some affordable counselling services.

Signing this form means that you understand the information and agree to take part in this study as a subject. In no way does this waive your rights nor release the investigators, or involved institutions from their legal and professional responsibilities. Please feel free to ask questions throughout the study. If you have any questions please contact:

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Academic Supervisor:	Ruth Grant Kalischuk, RN, PhD Faculty of Health Sciences University of Lethbridge Phone: (403)329-2747 E-mail: kalischuk@uleth.ca