



**MEANINGS OF WHEELCHAIR USE AMONG ELDERLY PERSONS WITH STROKE:  
A CONTINUITY THEORY ANALYSIS**

by

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**A thesis submitted in conformity with the requirements  
for the degree of Master of Science  
Graduate Department of Rehabilitation Science  
University of Toronto**

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**Master of Science, 2001**

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**Abstract**

This qualitative study investigated the lived experience of elderly stroke survivors who used prescribed wheelchairs in their home and community. The study involved semi-structured, in-depth interviews that were conducted with ten participants, aged 70 to 80, who had used a wheelchair for a mean of 5.6 years. Findings were interpreted using the life course continuity theoretical framework.

Three different categories of acceptance of wheelchair use were identified; reluctant acceptance, grateful acceptance, and internal acceptance. The wheelchair use meanings of increased mobility, varied social response, and loss of some valued roles were common to all three wheelchair use acceptance categories. Aspects of independence, freedom, and spontaneity varied in degree among the three acceptance categories. Community participation was both positively and negatively affected by wheelchair use.

As the wheelchair provided opportunity for increased continuity in the lives of these stroke survivors, it was accepted and appreciated more fully and viewed more positively.

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## **Chapter One: Introduction**

### **Rationale and Purpose**

A stroke, caused by either a blood flow interruption to the brain or a ruptured blood vessel in the brain, can result in a multitude of deficits. Motor and sensory deficits, cognitive and perceptual deficits, communication and swallowing difficulties, urinary dysfunction, and emotional alterations are all possible consequences of a stroke. Motor deficits often result in mobility impairment and the need for some type of mobility device, frequently a wheelchair. Persons with stroke are often referred to as 'stroke survivors'. This term is common in the research and clinical literature. The use of the term 'stroke survivor' in this study is not intended to take away from the personal nature, differences, and importance of individuals who have had a stroke, but is used as a recognition of an individual having lived through the actual stroke event and built up a new life after experiencing the event and its consequences.

Elderly stroke survivors are among the largest groups of individuals with disabilities who rely on seating and wheeled mobility interventions (Redford, 1993). It is estimated that 50,000 Canadians suffer a stroke every year and that just over one percent of the Canadian population, or about 300,000 persons are acute or chronic stroke survivors (Stroke Recovery Association of Ontario, 1995). The majority of these people are over the age of 65 and return to live in the community. (Heart & Stroke Foundation, 1996). Results of the 1991 Health and Activity Limitation survey show that more than 71,000 individuals over the age of 65 living in Canada reported using a wheelchair (Statistics Canada, 1991).

Personal experience as an occupational therapist in an interdisciplinary environment suggests that health care professionals, due to pressures of time and increasing caseload and

workload, generally prescribe wheelchairs for stroke survivors with minimal time spent thinking about and discussing how the survivor may view the new assistive device and how it may be perceived to affect the continuity of his/her life. While it is usually recognized that there are practical adjustments to be made when a stroke survivor starts to use a wheelchair for mobility (changes in living arrangements, etcetera) there are emotional and life course adjustments, including challenges related to community participation, that are often overlooked by health care professionals.

The dearth of research literature attests to the fact that there is insufficient knowledge with regards to the psychological and emotional adaptation that takes place with the advent of the need for assistive devices, including wheelchairs, among people with mobility impairments (Gitlin, 1998). Spencer (1998) addresses some of these issues in her article, 'Tools or Baggage? Alternate Meanings of Assistive Technology' in terms of the adaptation process of using assistive technology (AT) in everyday life. She argues, that in addition to practical reorganization that is necessary, requiring changes to be made to living arrangements and transportation, there is also an emotional adjustment that takes place, including the recognition of new or increasing disability and incorporation of a new image of oneself. In reviewing studies of AT with various patient populations, Spencer determines that the wheelchair user may take on a very different social identity. She argues that not enough about this identity and adaptation process is known and speaks of the implications for necessary further research.

Research is needed to understand these adaptations and experiences within the elderly stroke population. Research has been conducted, with regards to the emotional adjustments of various other patient populations, such as spinal cord injury and wheelchair use (Rush &

Ouellet, 1997, Cott & Gignac, 1999, Bates, Spencer, Young, & Rintala, 1993). These studies indicate that there are many factors that influence acceptance and use of wheelchairs by clients. These factors may include increased independence and attitudes of others. However, studies examining these issues in the elderly stroke population and how this psychological adaptation influences wheelchair usage, self image and community involvement have not been conducted.

Clearly, studies involving elderly stroke survivors who use wheelchairs in their home and community would be beneficial for a large number of Canadians and their health care providers. As the government and health care providers strive to provide client-centred, outcome-based effective care for the increasing number of elderly stroke survivors living in the community, studies that explore issues of experiences and meanings for this population equip stake-holders with the necessary tools for successful intervention strategies to improve the quality of life and meet the needs of this population of Canadian society.

Using qualitative methods, this study explored the experiences of elderly stroke survivors with mobility impairments who have used a wheelchair in their home and community for two years or longer. This study investigated the perceptions stroke survivors hold regarding how they view the wheelchair, what it means to them to use a wheelchair, and how the wheelchair affects their life course and activities.

### Conceptual Basis for the Study

The International Classification of Impairment, Disease, and Handicap (ICIDH) (WHO, 1980) provides the framework for this study. Continuity Theory is used to assist in interpreting results and expounded upon as it relates to the elderly stroke survivors who use wheelchairs.

## International Classification of Impairment, Disease, and Handicap.

The ICIDH is a classification system which was developed in 1980 by the World Health Organization to provide a scientific model of disability and the basis for common terminology for clinical use, data collection, and research. In 1995, revisions to the original ICIDH model began and work on this revised model, ICIDH-2, continues. The ICIDH-2 outlines three dimensions of a health condition, these being 'body functions and structure', 'activity', and 'participation'. Two 'contextual factors' impact the above dimensions, these being 'environmental factors' and 'personal factors' (WHO, 1999).

Impairments in body function and structure are problems in the physiological or psychological functions of body systems or anatomical parts of the body that lead to significant deviation or loss (WHO, 1999). These impairments, specifically mobility impairments, for the participants, led to the need for a wheelchair.

Activity Limitations are difficulties an individual may have in the performance of activities. An activity is limited when the individual, in the context of a health condition, either cannot perform the activity at all or has difficulty performing the activity in an expected manner (WHO, 1999). In this study, activity limitations lead to dependence issues, which played a large part in determining community participation. Due to activity limitations, the participants had to depend on caregivers to perform or help perform a variety of activities of daily living. Dependence issues include any need for care or service from others that the participant required. These dependence issues were important factors for the study participants when considering the meaning of wheelchair use and community participation.

Contextual factors include environmental factors and personal factors that may have an

impact on the individual with a health condition and that individual's functional state (WHO, 1999). Environmental factors are external to individuals and make up the physical, social and attitudinal environment in which people live and conduct their lives (WHO, 1999). Personal factors are features of an individual that are not part of a health condition or functional state (WHO, 1999). They include such things as age, race, gender, educational background, experiences, personality and character styles, social background, profession and past and current experience (WHO, 1999).

Participation is an individual's involvement in life situations in relation to health conditions, body functions and structures, activities, and contextual factors (WHO, 1999). Participation differs from the Activity dimension in that the core effect of the contextual factors involved in participation is at the societal category. The Activity dimension denotes limitations in performance of a particular activity by a particular individual. The Participation dimension, in contrast, denotes the restrictions in participation resulting from the external factors.

Using this classification system, this study examined the effects of body functions and structure, activity deficits, and contextual factors on views and meanings of wheelchair use and community participation of elderly stroke survivors who use a wheelchair in their home and community. More specifically, factors affecting community participation were divided into three main areas: Impairments in body function and structure, Activity limitations including dependence factors, and Contextual Factors including environmental factors and personal factors. Dependence factors defined as reliance on others, would be an aspect of impairments in body function and structure according to ICIDH-2. However, while listed under the impairment area, they were considered separately in the discussion and the model as these

seemed to be a very important factor in considering and actually participating in the community.

### Continuity theory.

Continuity theory was developed by Robert Atchley in 1989 in an effort to explain the common research findings that older adults, despite significant changes in health, functioning, and social circumstances, show considerable consistency over time in their patterns of thinking, activity profiles, living arrangements, and social relationships (Atchley, 1989). In this theory, continuity is seen as the persistence of general patterns rather than a sameness in the pattern details. In other words, continuity and change exist simultaneously in this theory as they do in the lives of middle-aged and older adults. Atchley developed Continuity theory based on the results of a twenty year longitudinal study of aging and adaptation. This present study used continuity theory to help explain how elderly stroke survivors view their wheelchairs and what it means for them to use a wheelchair. Continuity theory also assists in understanding patterns of community participation among the participants.

Continuity theory is a feedback systems theory that assumes that people need mental frameworks to organize and interpret their life experiences (Atchley, 1999). While there are a large array of specific mental frameworks, continuity theory focuses on global internal frameworks such as the self, personal goals or belief systems, and external patterns such as lifestyles, networks of social relationships and activity profiles. Individuals are believed to be dynamic and self-aware, using patterns of thought created out of a lifetime of experience to describe, analyze, evaluate, decide, act, pursue goals, and interpret input and feedback (Atchley, 1999). The primary goal of adult development is 'adaptive change', rather than 'homeostatic

**equilibrium? (Atchley, 1999).**

**Continuity theory speaks to how people attempt to adapt and the mental frameworks that they can be expected to use in doing so, however, it does not predict specific outcomes of adaptation or predict that the adaptation will be successful. The theory does state, however, that most people will try continuity as their first adaptive strategy.**

**Continuity theory addresses four dimensions of an individual over time, these being internal patterns, external patterns, developmental goals, and adaptive capacity. Internal patterns include ideas, mental skills, and information stored in the mind and are organized into constructs such as self-concept, world view, and belief systems. External patterns include such things as social roles, activities, relationships, and living environments. Developmental goals are ideals about oneself, activities, relationships towards which one wants to evolve. They include inner life and spiritual growth. Adaptive capacity is the extent to which one has the social resources and orientations needed in order to adapt to significant changes in physical and social circumstances (Atchely, 1999).**

**Within the dimension of adaptive capacity, Atchley outlines and describes six patterns of coping with functional limitations, based on activity levels. The first category, the continuity category, represents little change in either level or pattern of activity. The second category, consolidation, represents equilibrium in overall activity level but a change in the pattern of activity as a result of increasing some activities to offset declines in others. The decline with continuity category, the third category, represents a decline in overall activity level but consistency over time in the pattern of activity. The fourth category, disengagement, represents a sharp reduction in the number of activities, very little or no increase to offset activity losses,**

and a large decline in overall activity level. The fifth category, decline with some offsets, was defined by a decline in overall activity level but with some offsetting increases in a few activities. The sixth category, substitution, represents losses being offset by new activities, with a maintenance of activity level.

With the maintenance of activity level, in the continuity and substitution categories, there was found to be no negative effect on subjective well-being. With consolidation there also was no negative effect on subjective well-being. Similarly, there was no negative effect on subjective well-being with moderate decline in activity level. The negative effect on subjective well-being for those with profound activity decline was severe (Atchley, 1999).

Atchley confirms that very little research in gerontology has looked at the active adaptive response of the elderly to sudden or gradual onset of chronic illness (Atchley, 1999). In his 1999 book presenting the results of a twenty year longitudinal study of aging and adaptation, Atchley does consider elderly individuals who have functional loss. However, those with functional loss did not have impairment in any activities of daily living (ADL) and had minimal impairment in instrumental activities of daily living (IADL). This stands in contrast to this present study in which all participants had ADL and IADL impairment.

Prior to Atchley's 1999 book, Becker (1993) criticized continuity theory in that discontinuities, although expected in every life, are excluded or de-emphasized. Chronic illness was considered pathological aging in the beginnings of Continuity Theory (Atchley, 1989). Becker disputed this and felt that illness is often a part of life for elderly individuals. Becker contributed to the ongoing study of continuity in later life by studying continuity of life after stroke. She found that people unanimously viewed stroke as a profound disruption to their

**lives. The post stroke year was a time of life reorganization. The crisis of meaning resulting from the stroke could only be resolved by efforts to reestablish previous routines. The stroke survivors focused on everyday tasks that had provided them with a basic template for daily life in the past and had given their lives meaning. It was also found that those who suffered severe strokes struggled to regain a sense of continuity because they could not resume even simple tasks of everyday life. Many of these concepts will be discussed with regard to participants in this study and their use of a wheelchair.**

**Gitlin, Luborsky and Schemm (1998) also discussed the findings of their study of assistive device use and stroke survivors from the viewpoint of continuity and discontinuity, though they did not refer specifically to Continuity Theory. They found that the devices provided a mechanism for continuing valued roles and activities. However, they found device use simultaneously contributed to the emotional, physical, and social disruptions experienced in the stroke survivor's life. Mobility devices were only one category of device investigated in this work.**

**This present study uses continuity theory to better understand views, meanings, and acceptance categories of wheelchair use and patterns of community participation in elderly stroke survivors.**

### **Research Questions**

**Three main questions guided this study.**

- 1. How do elderly stroke survivors, having used a wheelchair for at least two years, view their mobility device?**

2.
  - a) What is the meaning of wheelchair use to elderly stroke survivors?
  - b) What factors are involved?
3. How does the use of a wheelchair by elderly stroke survivors affect their participation in the community?

## **Chapter Two: Literature Review**

The literature review is organized in six sections. These include: 1) Stroke, Mobility, and Mobility Devices; 2) Mobility Devices and Other Health Populations; 3) Stroke Survivors and Issues of Life-Course Disruption; 4) Stroke and Community Participation; 5) Assistive Device Use and Society Response; and 6) Impact of Powered Mobility Devices. Although the content in these sections is somewhat overlapping at times, the sectioning of the review provides structure to clarify important research findings that impact the development and understanding of the present study.

### **Stroke, Mobility, and Mobility Devices**

Mobility is crucial to our lives as humans, enabling us to do what is required and desired. It allows for function and exploration and is critical in our daily lives for vocational and avocational pursuits. Stroke survivors experience numerous losses (Secret & Thomas, 1999; Mumma, 2000). The loss of mobility, however, is one that is paramount in importance. In a study by Mumma (2000), perceived losses following stroke were explored from the perspective of the patients and the spouses. Sixty middle-aged and older couples in which one person had suffered a stroke were interviewed. Interestingly, the loss most often mentioned by stroke survivors was mobility.

The loss in mobility after stroke often requires use of mobility devices. The use of a cane, walker, or wheelchair provides the stroke survivor with the opportunity to be more mobile. However, wheelchair use for the stroke survivor is challenging physically, requiring much effort and expertise. Stroke survivors often only have use of the unaffected arm and leg for use in

propulsion (the hemiplegic pattern), thus impacting effort, difficulty, and frustration. Other wheelchair users are able to use two hands (two-hand pattern) to propel the wheelchair. To examine and compare hemiplegic and two-hand patterns of wheelchair propulsion during selected activities, Kirby, Ethans, Duggan, Saunders-Green, Lugar, and Harrison (1999), studied nine wheelchair users who used the hemiplegic pattern of one arm and one leg to propel the wheelchair were compared with nine matched controls who used the two-handed pattern on six different aspects of wheelchair use (propelling and stopping the wheelchair, forward and backward, on a category surface and on a 5 degree incline). Overall, they found that wheelchair users who use the hemiplegic pattern experience more difficulties than those using the two-handed pattern in all the testing.

There have been few studies done that have specifically examined stroke survivors in relation to the psychosocial adjustments that take place with mobility device usage. It is certainly believed to be worthy of study with other populations, as noted in the next section. The work that has been done involves the stroke survivor along with other populations with regards to mobility use or investigates the stroke survivor with regards to all assistive technology (AT), not just mobility devices. Gitlin, Luborsky, and Schemm (1998) did such a study, including mobility devices among other devices in their research of stroke patients concerns, perceptions and beliefs about assistive devices prior to discharge home from a rehabilitation hospital. They found that stroke patients expressed concerns about social acceptance and personal identity with regards to mobility devices, even though these devices were also viewed as providing an opportunity for independence. For some respondents in the study, however, the alternative to not using a device, such as confinement or immobility, helped

them in their acceptance of the device. They suggested that “devices may be visual reminders of the loss and disruption caused by the stroke and yet provide a mechanism for continuing valued roles and activities”(Gitlin et al, 1998, p.177). These authors also suggested that further research is required to assist in understanding the experiences of device use with this population following hospitalization and over time.

### Mobility Devices and Other Populations

Various other health populations, other than stroke, have been studied with regards to psychosocial issues and use of mobility aids. In this body of literature, technologies to aid in function after disability, including wheelchairs, can be seen as tools, but can also be seen as something that underlines the disabled status (Lupton & Seymour, 2000; Rush & Ouellet, 1997). The benefits and drawbacks of mobility device usage are outlined in various studies (Lupton & Seymour, 2000; Rush & Ouellet, 1997; Cott & Gignac, 1998).

Although positive aspects of technology, and specifically wheelchair use, can be appreciated, the overall view of the device may still be negative. Research, conducted with fifteen people aged 19 to 46 who had various physical disabilities, found that technologies were valued for ‘allowing them to tame the disorderly aspects of their bodies and thus to facilitate social integration’ (Lupton & Seymour, 2000, p 1857). In speaking of wheelchair use specifically, positive aspects such as increased mobility and increased social interaction were discussed, as well as negative aspects such as the wheelchair being seen as a signifier of disability, detracting attention away from identity and individuality of the user. Overall, in this study, it was found that technologies were conceptualized in two dominant ways. First, some

technology were seen as tools that assisted bodily function and contributed to the experience and presentation of the body/self. These technologies were 'incorporated unproblematically into their notions of self and body' (p 1861). However, some technologies, such as wheelchairs, were seen as 'underlining' the participant's status as disabled and so were viewed with greater ambivalence. Some participants rejected these technologies completely, saw them as apart from themselves, even though they may have enhanced bodily capacities. In this study, wheelchairs were seen overall as a signifier or symbol of disability.

Rush and Ouellet (1997) interviewed eleven nurses regarding mobility aids and the elderly and also found that the mobility aid can become a visible symbol of disability and even stigmatization. These nurses felt that to their elderly clientele, the mobility device was seen as a form of exposure, letting those who view the person with an device recognize that they have a weakness, that they are not 'normal' in a sense. The use of a mobility device was also felt to be a loss of pride and of dignity for the elderly, altering self-identity, and causing them to withdraw from the larger environment and into their immediate environment. It is concluded that there is a "complex interplay of mental processes influenced by internal and external forces that must be explored more fully before an elderly client can perceive the mobility aid as a tool for living"(Rush & Ouellet, 1997, p.15).

Acceptance of the wheelchair, or mobility device, has not been found to be quick or easy. In fact, acceptance may take years in some cases. Bates, Spencer, Young, and Rintala (1993) studied the adaptation to wheelchair use experienced by a 30-year-old man with acquired paraplegia. They found that the man's initial attitudes regarding wheelchairs were prejudicial and that this hampered his ability to see the chair as a useful tool for mobility and independence.

**They suggested that there needed to be an emotional acceptance of the wheelchair. They also suggested that the process of adaptation to a wheelchair use takes place over a period of years and requires an emotional adaptation and new self-image and body image that includes the wheelchair.**

**There are many factors that have been found to affect acceptance of mobility devices. Initial prejudice toward the device, as found in the study of Bates, Spencer, Young, and Rintala (1993) can be a factor. Fear of attitudes of others and stigmatization have also been found to be factors in acceptance of these devices (Cott & Gignac, 1999; Rush & Ouellet, 1997). Genuine acceptance of mobility device usage often comes with seeing the need for the device, testing it out and seeing the benefits such as the expanding of the user's spatial boundaries and maintaining independence which preserves self-integrity and self-identity (Cott & Gignac, 1999; Rush & Ouellet, 1997).**

**Even once a mobility device is accepted by the user, there can be frustrations in it's usage. In a study done by Pierce (1998), nine people between the ages of 20 and 52 who used wheelchairs because of a physical disability (not described) were interviewed. Participants expressed feelings of frustration concerning wheelchair access issues. Four sub-themes related to this frustration included issues of independence, attitudes of others towards people with disabilities, others' lack of understanding of the situations of individuals with disabilities, and lack of involvement of people with disabilities in decisions regarding the development of community facilities for disabled persons.**

**The use of mobility devices has been found to alter self-identity in many cases (Rush & Ouellet, 1997; Bates, Spencer, Young, & Rintala, 1993; Lupton & Seymour, 2000), and maintain**

**self-identity through independence and increased mobility in others (Cott & Gignac, 1999; Rush & Ouellet, 1997). Clearly, there are many complex issues in the acceptance and usage of mobility devices among various health populations and ages.**

### **Stroke Survivors and Issues of Life-Course Disruption**

**Sociological literature on chronic illness refers to the concept of ‘biographical disruption’. This concept was first introduced by Bury (1982) in his study of people with rheumatoid arthritis. He outlined three aspects of disruption: 1) disruption of assumptions and behaviours, 2) disruptions in explanatory systems that require rethinking of one’s biography and self-concept, and 3) the response to disruption. Recently, Williams (2000), reflected on the strengths and weaknesses of biographical disruption, including the idea of ‘normal illness’, the importance of timing and context, the significance of continuity as well as loss, and the role of biographical disruption in the etiology of illness.**

**Corbin and Strauss (1987) continued to develop the biographical impact of chronic illness introducing the ‘biographical body concepts’ (BBC), defined as the conceptions of self arising directly or indirectly through the body, evolving over the course of biographical time. They stated that disruption to the BBC chain requires biographical work in order to be put back together after chronic illness. Biographical ‘accommodation’ must be made requiring much work on the part of the person with chronic illness.**

**Charmaz (1987, 1995) also spoke of disrupted plans and altered lives in chronic illness. She introduced identity categories of those suffering from chronic illness and spoke of adapting to impairment and resolving the lost unity between body and self with regards to changing**

**identity goals.**

Various studies have investigated stroke as biographical disruption. Kaufman (1988) wrote about the 'illness careers' of two elderly stroke survivors, addressing issues of continuity of life and meaning of illness, rehabilitation, and recovery. Pound, Gompertz, and Shah Ebrahim (1998) challenged biographical disruption's assumption that the lives of the chronically ill have previously been untouched by crisis or struggle. They found that stroke was not such a disruption to the lives of the elderly, socially disadvantaged stroke survivors in their study.

It has been found that adults who are stroke survivors, even those who do not have to rely on a wheelchair for mobility, have difficulties with adapting to limitations that the stroke brings and their changed lives. Studies of psychosocial issues with stroke survivors often do not differentiate different mobility categories, but group stroke survivors together in exploring issues of life-course disruption. The effect of wheelchair use on life-course continuity/disruption in stroke survivors has not been investigated.

Studies have found that the advent of a stroke brings about numerous changes, disrupting the normal course of the individual's life. Losses in many aspects of life have been outlined, including loss of activities, abilities and characteristics, and independence (Mumma, 2000). These losses change internal and external patterns within the lives of the stroke survivors, and can bring about changes in self-identity and self-concept (Ellis-Hill & Horn, 2000), depression (Singh, Black, Hermann, Leibovitch, Ebert, Lawrence, and Szalai, 2000), decreased subjective well-being (Wyller, Holmen, Laake, Laake, 1998), and decreased quality of life (King, 1996; Astrom, Asplund, & Astrom, 1992). Secrest and Thomas (1999) interviewed 14 stroke survivors with a two year median length of time since stroke. They found that the

**participants experienced a world of loss and effort with interrelated themes of independence/dependence, in control/out of control, and connection/disconnection with others. These themes were brought together in the fundamental aspect that there is a sense of continuity that coexists with discontinuity in the experience of self.**

**Becker (1993) studied 100 stroke survivors over a five year period, looking at life-course disruption and found that these individuals viewed stroke as a profound disruption to their lives and questioned whether their old selves still existed. It was found that the post-stroke year emerged as a period of life reorganization. The subjects became self-absorbed as they struggled to reconcile the person they once were with the non-functioning person that they had become. On return to their homes, the stroke survivors found that their sense of loss was reinforced and they had difficulty returning to previous roles and had increased social isolation.**

**In addition to the disruption in the life of the stroke survivor, the advent of stroke changes roles and relationships within the family life of the stroke survivor also. Jongbloed (1994) addressed adaptation to stroke in her single case study with a woman who experienced a stroke. Analysis of five interviews, conducted over two years, revealed role changes and changes in responsibilities of this woman and that of her husband. There was a major restructuring of the stroke survivor's life as well as that of her husband. Life-course disruption, then, is evident in family of the stroke survivor also. Research has also found that business and other social networks are disrupted after stroke (Burton, 2000).**

**This disruption in the life of the stroke survivor requires work and time to recover some sort of balance and continuity in life. Buscherhof (1998), a psychiatric nurse who is also a stroke survivor, described eight stages in her emotional recovery from stroke. These included**

denial, grieving, transition from caregiver to care-receiver, developing optimal independence, building a new or renewed system of social support, successful reintegration into the community, acceptance of any remaining disability, and return to a quality life. She expressed that the development of a new sense of self is a major psychological task for those who must adapt to significant neurologic loss.

The studies outlined above involved stroke survivors in general and did not look at mobility issues specifically. It is entirely possible that those stroke survivors who require the use of a wheelchair might experience even more difficulty with these issues of self image and life- course adaptation than those who do not, given the additional burden of mobility impairment.

### Stroke and Community Participation

In stroke rehabilitation, distinct physical functioning is often emphasized. The stroke survivor may attend therapy to increase his/her strength in an extremity or the range of motion of a certain joint. However, the overall functional category itself, in particular the category of community and social participation may be more important to the stroke survivor. Burton (2000) tracked the experience of six stroke survivors admitted to a rehabilitation unit after stroke. The stroke survivors were followed for at least 12 months after stroke. The data showed that recovery from stroke involved restructuring and adaptation in physical, social and emotional aspects of an individual's life. It was found that the participants focused on the social context of recovery where engagement in the social world was emphasized over discrete physical function. Isolation was also a common finding among the participants, identifying waiting for help or

**waiting for family and friends to come as being a key feature of the isolation. Reintegration into the social world is very important to the stroke survivor.**

**Social isolation, as seen in the study mentioned above, is a common finding in the studies of stroke survivors and community participation. De Sepulveda and Chang (1994) in assessing 75 stroke survivors, found that persons with functional disability following stroke had decreased social contact and perceived less availability of social resources. Pound, Gompertz, and Ebrahim (1998) explored the consequences of stroke by interviewing forty stroke survivors and found that the participants described the loss of social contact that accompanied changes in their daily lives, including difficulty with leaving the house, problems with walking and ADL tasks, among other areas. The participants also expressed the loss of valued roles which had been embedded in the everyday functions that they had previously performed.**

**The importance of family in the issue of community participation in this population has been seen in some studies. Needing assistance from family or friends has been shown to be a key feature of social isolation (Burton, 2000). Clark & Smith, (1999) found that family functioning was an important determinant of social activities and of the activities the stroke survivor actually does, rather than those the stroke survivor is capable of carrying out. Social isolation among these stroke survivors was found to lead to depression. Morgan and Jongbloed, (1990), in studying thirty stroke survivors who had had a stroke within the previous fifteen months and had returned home, found that the quality of an individual's relationship with family and friends is often the most influential factor determining social and leisure activities following a stroke.**

## Assistive Device Use and Society Response

Stroke survivors and other mobility device users have concerns about social acceptance. For some, the mobility device has been perceived to provoke stigmatization. As mentioned in a previous section, nurses in one study felt that their elderly clientele felt stigma due to their age which was then compounded by the stigma of using a mobility device. The nurses likened using a device to a form of exposure, letting those who view the person with an device recognize that they have a weakness, that they are not 'normal' in a sense (Rush and Ouellet,1997).

Also, as mentioned in a previous section, seniors with osteoarthritis and/or osteoporosis, using mobility devices felt some stigma when using the devices in the community, however, they were willing to risk stigmatization to achieve their goal of maintaining their independence (Cott and Gignac,1999).

According to Goffman (1963), stigma refers to anything that disqualifies individuals from full social acceptance, regardless of whether people are responsible for their condition. Society response to various conditions that is negative can be referred to as stigma, as Goffman has defined it. However, the term 'society response' can be used as an umbrella type of term that would incorporate the idea of stigma but would also include other responses, such as positive or neutral responses from people or society as a whole. Thus in this study, 'society response' will be used to capture these concepts.

In a 1991 Harris poll it was found that 58% of people without disabilities who were interviewed reported that they felt anxious, uncomfortable or embarrassed in the presence of a person with a disability. Forty-seven percent of those interviewed reported that they actually felt fear (Harris & Associates, 1991). This fear could be based on many factors. Covington (1998),

relating his own personal experience of being visually impaired and the stigma he felt using a white cane, speaks of reasons to explain the fear factor of those without disabilities towards those with disabilities, including historical roots. He recognizes the media's influence on this issue and the impact of design barriers on assistive device use and attitudes towards those with disabilities.

Public reaction to assistive device use is not always found to be negative. In a study of American scientists and engineers who had various disabilities, and used a number of different assistive devices (communication devices, mobility devices, personal care/hygiene devices), Brooks (1991) found that 57% said that using devices is always socially acceptable. The respondents found that general public reaction to the use of assistive devices was 'about average' with more respondents observing positive rather than negative reactions from the public.

Pippen and Fernie (1997) interviewed twenty-two elderly people who used a walker because of increasing impairments. The walker enabled the user to become more independent. They found that personal acceptance of the walker incorporated issues related to device appearance and stigma and enhancement of individual autonomy. It was also found that acceptance of the walker was dependent upon the context. Although participants were initially concerned with the negative image the walker had, this concern was temporary and limited to the first mobility device that was used. It was found that the realization of increasing impairment and admitting dependence was more problematic for users than issues of appearance.

The issue of society response and the elderly stroke survivor using a wheelchair in the

community has not been investigated. There is a need for further research among this population to more fully understand the lived experiences of this group of individuals in our Canadian society.

### Impact of Powered Mobility Devices

There are very few studies on the impact and advantages of power mobility devices. As with manual wheelchairs, research tends to focus on the technical aspects of the devices, exploring seating pressures, safety concerns, design issues, and other technological issues. Two articles that explored wheelchairs and lifestyle issues are outlined below.

Using a structured interview format, Buning & Schmeler (1999) interviewed eight people with various progressive diseases who had previously used manual wheelchairs but changed to a power mobility device (PMD). Results indicated that use of PMD's was associated with a significant increase in adaptive performance in everyday life. It was found that with a PMD participants were able to pursue previously valued interests, assume responsibility, and enact new and old roles that brought meaning in their lives. The greatest increases were found in independence, quality of life, happiness, performance, ability to adapt to activities of daily living, and ability to take advantage of opportunities.

Miles-Tapping (1996) conducted an ethnographic study with a convenience sample of fifteen power wheelchair users, age 35 to 75. It was found that despite difficulties encountered using the device, the power wheelchair users felt empowered by their mobility aid. The power wheelchair widened their world, enabled the users to be more productive, enjoy more leisure, and accomplish more self care than prior to their use. It was concluded that power wheelchairs

**contribute substantially to independent living styles for those with mobility impairments.**

**The powered mobility device, as shown in these two studies, has many benefits for the user. Stroke survivors were not specifically studied with respect to powered mobility device usage. The benefits experienced by other populations would be thought to occur among stroke survivors also. Further research needs to be performed to shed further light on power mobility device use and stroke survivors.**

### **Summary**

**In summary, stroke survivors, even without regard to wheelchair use, undergo a major life course disruption with changes in self-image and self-identity with community participation being impacted. Stroke survivors prior to discharge from hospital have concerns about social acceptance and personal identity with regards to mobility devices. Individuals with varying disabilities using assistive devices, and specifically mobility devices, can feel stigma in the community, but device use and acceptance is not always dependent on society's response that the device user encounters. Adaptation to wheelchair use in other populations is a lengthy process, and power wheelchairs can bring about increases in independence and quality of life. More research is needed to examine the many factors that influence acceptance and use of assistive technology, including wheelchairs, by various client populations, not just stroke survivors.**

**Research that specifically examines the life-course disruption, psychological and personal adjustments in elderly stroke survivors who use wheelchairs post discharge from the hospital is lacking. As mentioned, adjustment or attitudes to wheelchair use prior to discharge**

has been studied as have changes in stroke survivors' personal identity issues without regard for wheelchair use. Research has shown that AT users with diagnoses other than stroke experience varying responses from society and require periods of adjustment to device use. Gitlin (1998) discusses the lack of knowledge with regard to the personal and emotional adjustment that takes place with AT devices. She recognizes that there is a dearth of knowledge regarding the experiences of older adults who confront the need for assistive devices late in life as a result of a first-time disabling condition. This study, exploring how elderly stroke survivors view wheelchair use, the meaning they attribute to wheelchair use, and how this affects their lives post-discharge from the hospital, furthers the knowledge in the areas of AT and stroke.

## **Chapter Three: Methodology**

### **Design**

This qualitative study involved in-depth interviews with a sub-sample of respondents obtained from an original study entitled, “Factors influencing the occupational performance of elderly stroke survivors who use prescribed wheeled mobility systems in the home environment: Users’ and caregivers’ perceptions” (Reid, 2000). This original study will hereto be called the primary study.

Qualitative research methods are the method of choice when the experience of a situation or of people, the thought processes, and feeling and emotions are being explored (Strauss & Corbin, 1998). Research that is exploratory or descriptive and that stresses the importance of context, setting, and the participants’ frame of reference is well served by qualitative research methods (Marshall & Rossman, 1989). This researcher, prior to this study, had listened to recorded qualitative interviews and had conducted interviews for the primary study, and in this way the purpose, questions, and processes for this study were developed. This process of using an existing qualitative data set as one data source while continuing to refine the study purpose, questions, and data collection processes is outlined by Hinds and Vogel (1997). Demographic data from the primary study, in addition to further demographic data collected specifically for this study, was used for some of the data analysis. The demographic data were the only material from the primary study that was used in this study. Photographs of the participant’s wheelchair were also taken to aid in the recording of wheelchair style and condition.

### **Sample**

**The sample for this study involved a sub-sample of participants recruited from the above-mentioned primary study. The inclusion criteria for stroke survivors in that study were as follows. Subjects had to:**

- **be over the age of 65**
- **live at home**
- **have been using a prescribed wheeled mobility system for at least one year**
- **have someone who helps them with their daily activities**
- **live in the Metropolitan Toronto area**
- **speak and understand the English language**
- **be cognitively competent to use a wheelchair and report their evaluation of its use in an interview.**

**The subjects were recruited from the Stroke Recovery Association of Ontario, the Heart and Stroke Foundation of Ontario, St. John's Rehabilitation Hospital, Comprehensive Rehabilitation and Mental Health Services, Central Neighbourhood House, Etobicoke Community Care Access Centre, Boost Downsview Services for Seniors, Toronto Rehabilitation Institute, and Baycrest Geriatric Centre.**

**The sub-sample invited to participate in this study were those participants who expressed themselves well in the primary study (as suggested by Dr. Milada Disman, personal communication, October 26, 1999). Ten stroke survivors participated in this study and comprise the sample for this thesis.**

**Participant demographics are shown in Appendix A. Participants were between 70 and 80 years of age, with eight males and two females. Time since stroke ranged from two years to**

sixteen years. Ethnically, there were two black and eight white people participating. All participants were married and living with a spouse who was acting as the main caregiver. One participant also relied on a homemaker to assist with daily dressing and bathing due to her husband's arthritis. Education ranged from grade school to university degree, with two participants having a grade school education, five participants having a high school education, and three participants having a university or college education. Yearly household income varied, however only one participant had a yearly income of \$50,000 or more. Two participants refused to disclose their income category. Eight of the participants owned their own home and seven lived in a house while three lived in an apartment or condominium. Although not shown on the table, two participants were completely wheelchair dependent while eight participants used the wheelchair inside and outside the home but were able to ambulate for short distances with a walker or cane. All participants owned and used manual wheelchairs, however one participant also owned and used a power wheelchair and one participant also owned and used a scooter. For the most part, these participants used the manual wheelchairs for indoor mobility and the power devices for outside mobility.

### Ethical Considerations

Approval was received for the primary study from the Human Subjects Review Committee at the University of Toronto. Informed, written consent for involvement in the primary study was obtained from all participants using the Consent Form (see Appendix B ). On this consent form was the possibility of a further interview to explore some information further. On January 11, 2000, the interview guide for use in the interviews for this study, was approved by the same review committee (see Appendix C for approval letter).

Potential participants were contacted by phone by this investigator regarding participation in this study and gave verbal consent over the phone if they wished to participate. Participants who were willing to participate were informed that they could choose to withdraw from the study at any time without consequence.

### Risks and Benefits

There were no risks involved in participation in this study other than the possibility of discomfort with speaking about the wheelchair and its effect on the lives of the participants. In this regard, participants were interviewed in the comfort of their own home and told that they could choose not to answer any question that they felt uncomfortable answering. The investigator, who was also the interviewer, attempted to make the interview as non-threatening as possible. The participant was invited to stop at any time and take a break if desired.

There were no direct benefits from participation in this study. At times, participants, knowing that the interviewer was an Occupational Therapist, asked for advice or information with regards to various wheelchair or equipment issues. Requests of such nature were deferred until after the interview was completed. Information regarding various service providers and equipment issues was given at that time.

### Procedures and Data Collection

Prior to any interviewing, assumptions or biases on the part of this researcher were 'bracketed' (Moustakas, 1994; Ahern, 1999). This process of bracketing is central to qualitative research, and involves setting aside, as much as is possible, all preconceived experiences to best understand the experiences of the participants in the study (Moustakas, 1994). Biases and prior assumptions of this researcher were explored and recorded on paper in an ongoing journal of

thesis process and ideas. Because of this investigator's occupational therapy background and knowledge and extensive prior work with stroke patients, personal biases included the assumptions that independence and health are very important to individuals, that activity is central to health and well-being, as well as other biases. Because of involvement in interviewing stroke survivors and caregivers for the primary study, this investigator was aware of some of the issues surrounding wheelchair use in the home and community on the part of both the stroke survivor and the caregiver. These biases also had to be purposely set aside. Recognizing my status as a middle-aged, middle-class professional with a healthy body and mind with all the beliefs and values and assumptions that go along with that status, was also vital.

To identify potential participants, written transcripts from the primary study were read, examining the documents for the ability of the participants to express themselves verbally. In addition to this review, this investigator, having performed some of the interviews for the primary study, knew of some potential participants who met the inclusion criteria. As mentioned previously, these potential participants, having already been made aware from the primary study of the possibility of further interviews, were contacted by phone to ask their verbal consent to the further interview.

Upon consent, a mutually convenient time was arranged for the interview. All interviews took place in the subject's home with the one exception being one interview which took place in a private room of a rehabilitation hospital due to the fact that the participant was recovering from a fractured hip at the time. All interviews were conducted by this investigator. The interviews took approximately one and a half to two hours with each participant. The

qualitative interview took place first using the interview guide (See Appendix D for Interview Guide) for an outline in questioning. Questions were not necessarily asked in the order on the guide but all questions were answered by the participants. With the exception of one interview, the participant was interviewed alone. The one exception was the addition of the participant's wife in the room for at least half of the qualitative interview. The participant and his wife requested her presence to increase the comfort category of the participant.

In performing the interview, the interviewer positioned herself as a learner, asking the participant's to give their 'expert' opinion on life as an elderly stroke survivor using a wheelchair in their home and community (as seen in Sword, 1999). This seemed to be well received by the participants who shared openly and comfortably.

After the qualitative interview was completed the data sheet (See Appendix E) was filled in by the interviewer with input from the participant and then a photograph of the wheelchair was taken. The qualitative interviews were audio taped, however, the remainder of the interview was not.

Field notes were generated immediately after the interview, denoting any information deemed to be important, such as emotional responses, interview environment, and interruptions (See Appendix F for field note form). Interviews were transcribed verbatim as promptly as possible after the interview was completed.

Interviews were conducted from March 6, 2000 to August 16, 2000. Transcription and coding took place from March 7, 2000 to September 2000.

### Data Analysis

Data analysis involved an inductive approach, using a constant comparative process.

The transcribed interview was coded, using open coding initially. Open coding is a process through which concepts are identified and their properties and dimensions are discovered in data (Strauss & Corbin, 1998). This can be done in several ways. In this study, transcribed interviews were coded by analyzing whole sentences or paragraphs. The major idea was then determined and coded appropriately.

Inter-coder reliability and the utility and appropriateness of the initial coding were assessed by a member of this researcher's programme advisory committee, Dr. Cheryl Cott, and this researcher by independently coding pages of text with subsequent comparison. There was found to be minimal discrepancies in the coding. Minor modifications to the coding system were made as required. The coding scheme with definitions is found in Appendix G.

A qualitative computer software programme (QSR NUD\*IST 4, 1997) was used to assist in the coding and retrieval processes. Transcribed interviews were imported into the programme. The interviews were then coded on the computer screen. Once all interviews were transcribed, imported into the NUD\*IST programme and coded, it was possible to produce data from all interviews for each code. This retrieved synthesized data were used for axial coding.

Process files, kept in a journal, contained information about the dynamics of the research process and were developed and ongoing throughout the data collection and analysis. (Kirby & McKenna, 1989). The process files allowed for recording of progression of research, thoughts of the researcher, development of themes, and other information deemed relevant and important to the research process. Themes that emerged from the data were explored and recorded in the process files. As these themes emerged, questions in later interviews were added to pursue these concepts and ideas with remaining participants.

As mentioned, after open coding of all interviews was completed, axial coding was undertaken. Axial coding involves re-assembling the data relating categories to their subcategories in order to form more precise and complete explanations about phenomena (Strauss & Corbin, 1998). Categories were then integrated and refined. Analytical and conceptual memos, both written and diagrammatic, were used throughout the analysis to help clarify and develop and explore emerging themes.

Once data were completely analyzed and themes fully developed, a 'member check' was performed (Rowan & Huston, 1997), in order to improve the validity of the study, and allow participants to respond to the recorded findings and analysis. A summary sheet of the findings of this study was mailed to two participants, and after 7 to 10 days, a final telephone interview was conducted with them. The purpose of these interviews was to enhance the credibility of the study findings by giving these respondents an opportunity to assess and discuss the validity of the findings and analysis to see if they regard the findings as a reasonable account of their experience (Mays & Pope, 1995). The input and feedback from these telephone interviews was incorporated back into the analysis.

Throughout the following results and discussion sections the terms 'most', 'many', 'few', and 'all' will be used as related to number of participants and various phenomenon. For clarity in understanding and consistency in usage, these terms, as related to this research, are defined as follows:

'most' = 7 or more participants, 'many' = 5 or 6 participants, 'few' = 3 or 4 participants, and 'all' = all ten participants.

## **Chapter Four: Results**

### **Views of Wheelchair with Corresponding Categories of Acceptance of Wheelchair Use**

In the interviews, participants were asked questions about how they would describe themselves, how they viewed the wheelchair, how they felt people reacted to them in a wheelchair, and what difference the wheelchair made to their lives. The interviews yielded a large amount of data. As data were analyzed, the three research questions guiding this study provided a framework for grouping of themes resulting from the data analysis. The framework for the presentation of results is as follows: (a) Views of Wheelchair with Corresponding Categories of Acceptance of Wheelchair Use (b) Meanings of Wheelchair Use (c) Impact on Community Participation. These theme groupings will be discussed in separate chapters. Sub-themes and related factors will be discussed as they pertain to the main theme of the chapter. All names used in the text are pseudonyms in order to protect the confidentiality of the participants.

#### **Views of Wheelchair and Corresponding Categories of Wheelchair Use Acceptance**

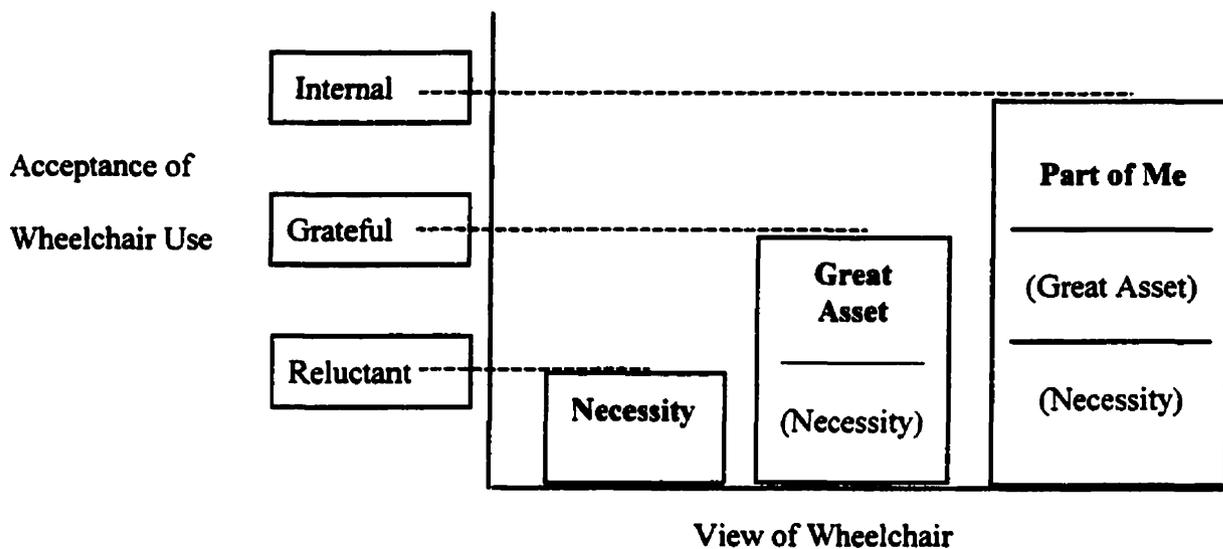
This chapter will begin with views of wheelchair with corresponding categories of acceptance of manual wheelchair use. Powered mobility will be considered separately. Factors affecting acceptance and views and other related issues will then be discussed.

Generally speaking, the wheelchair and its use were viewed positively by the participants. While the participants could identify difficulties related to using a wheelchair and a few participants expressed that they wished that they did not have to use it, they generally

**spoke favourably about having a wheelchair. The following sections will describe the differing views that the participants had regarding the wheelchair and their category of acceptance of wheelchair use.**

**There were three views of the wheelchair. Each represented a category of acceptance of wheelchair use. Figure one illustrates these views and acceptance categories, with the three views of the wheelchair on the x-axis and the corresponding acceptance category of wheelchair use on the y-axis. As will be mentioned later, participants readily spoke of the pros and cons of using a wheelchair but did overall think positively about the wheelchair.**

**As shown in the figure 1, the first view of wheelchair was as a necessity only. This view represented reluctant acceptance of wheelchair use. The second view was where the participant viewed the wheelchair as not just a necessity but also as a great asset. The corresponding category of acceptance for this view was grateful acceptance. The final view of the wheelchair was that one viewed the wheelchair as a part of him/herself in addition to viewing the device as a necessity and as a great asset. The corresponding category of acceptance for this view was a complete internalized acceptance. These views of wheelchair and acceptance categories will be examined in turn. Factors affecting the views of the wheelchair and corresponding acceptance categories will then be presented.**



**Figure 1.** Views of wheelchair with corresponding categories of acceptance of wheelchair use

**The wheelchair is a necessity - reluctant acceptance.**

Four participants viewed the wheelchair as a necessity only. While they viewed the wheelchair positively, they did not talk at length about the benefits of wheelchair use, but more about the necessity of its use. These participants expressed the view that they would rather that a wheelchair was not necessary but recognized that in view of their physical problems and dependence on others, it left them no alternative but to use the wheelchair- it was a necessity: “Without it (the wheelchair) I couldn’t get anywhere. Without the chair, I’d just have to put up with it. It’s a necessity” (Mr. K.L.). So while these participants could list benefits of wheelchair use, and felt positive about the wheelchair, they did not speak at length of it as an asset or aid for their daily lives.

These participants who viewed the wheelchair as a necessity reluctantly accepted their

need for a wheelchair. They were not happy with the fact that they needed a wheelchair but did realize that life and their activities would be negatively affected without it. The physical condition that they found themselves in after the stroke had left them no alternative but to use the wheelchair. This is seen in the quotation below by one such participant when asked how he felt about the fact that he needed to use the wheelchair: "Not a thing I can do about it. I've come to accept it. That's it. I don't like it but .... maybe I...I figure my age and what has happened to me made me where I am" (Mr. S.T.). Another participant reluctantly accepted the wheelchair but had a goal to get rid of it eventually: "...And I'm going to survive one stage further. I'm going to walk out of this (wheelchair) one day" (Mr. O.P.).

All participants in this group were male and were able, to some extent, to walk with a walking aid inside their home. With the exception of one participant, those in this group also used the wheelchair inside their homes. The one exception was a participant who used a quad cane for all in home mobility. It is worthy of noting that this participant had an ill-fitting wheelchair that he found quite uncomfortable. The wheelchair was a low end wheelchair with no cushion or proper arm support. One participant in this group had power mobility in addition to his manual wheelchair and another participant in this group expressed his desire to acquire a powered mobility device, listing many of the frustrations of his manual wheelchair and many anticipated benefits of powered mobility.

#### The wheelchair is a great asset - grateful acceptance.

For four of the participants, the wheelchair had become more fully incorporated into their lives. The wheelchair was viewed as a great asset in addition to being a necessity. The participants voicing this view of the wheelchair spoke more of the benefits than the problems

with wheelchair use. They seemed to fully recognize the positive impact of the wheelchair on their day to day lives, reflecting the emotional impact of the thought of the wheelchair as a tool for daily living. They were thankful for the wheelchair and for what it allowed them to do: "Well, using the wheelchair doesn't make my life harder. Using the wheelchair makes my life easier" (Mr. I.J.). This same participant spoke of the benefit of using the wheelchair to combat the effects of the stroke: "But now I use the wheelchair I feel that I have conquered my illness" (Mr. I.J.).

The wheelchair was gratefully accepted and had become an accepted part of life and daily routine with those expressing this view. The wheelchair brought increased security and confidence in mobility, and was necessary for proper seating and for indoor and outdoor mobility. One participant expressed this grateful acceptance in this way:

If I didn't have the wheelchair I'd be lost. It's the thing...it's a necessary thing for anyone that's crippled. You know, that can't walk very much. It's a must to have it - it's a must. It's a great asset. It's a great asset. You can fold it, put it in the car, and go on your merry way when you get there. You can take it out of the car and wheel it to wherever you want to go (Mr. A.B.).

The wheelchair was seen as both a necessity and as a great asset.

The participants in this group, included three males and one female. Of the four participants, only one required a wheelchair full time for mobility inside and outside his home. The others were able to use either a quad cane or mobility walker in their homes, using the wheelchair for some indoor mobility and for outdoor mobility.

The wheelchair is a part of me - internal acceptance.

With this final view, the wheelchair was not just a part of a routine of daily living, a necessity and a great asset, but a part of the participant themselves. The participants acknowledged the decreased abilities of his/her physical body and were willing to substitute mal-functioning body parts with the wheelchair. Two of the participants expressed this idea. One participant with left hemiparesis referred to the wheelchair as his left foot: "It's my left foot! Can't say my right hand. Can't say my right foot. It's an extra foot. Makes me comfortable. Let's put it that way" ( Mr. E.F.). Later the same participant expressed the thought again: "Most important thing, as I said before, it gave me an extra leg.... gave me a little more strength, confidence to move about, to be more mobile" (Mr. E.F.). The other participant, after speaking of the benefit of mobility and comfort in the wheelchair, and the wheelchair 'accommodating' her, said: "So the wheelchair is a part of me now" (Mrs. G.H.).

These quotes and other such statements made, show that there was definite internalized, emotional acceptance of the wheelchair into the lives of these two participants. The wheelchair had become more than a method of transportation. It had become a substitute body part and a definite part of who they now are. It is interesting that the view of the wheelchair being a necessity and a great asset can also be seen when reviewing transcripts of these two participants. They spoke gratefully about the wheelchair and its benefits and the need for it in their everyday lives:

I'm thankful that I got it. I don't have to stop to go to be outside. To go out somewhere. I'm thankful that it's portable enough to go in the car. I got a nice station wagon. It slides right in. You don't really have to lift it much. Just very slight really. About an inch or two off the ground and it goes in easily. And even the Wheeltrans like it. It's the

portable - transférable. I can go with the wheelchair or without the wheelchair. But usually I go with the wheelchair. I'm afraid to go the long distance.... afraid to walk it (Mr. E.F.).

There were only two participants in this group. One was male and one was female. The male was the longest wheelchair user in the study, having used a wheelchair for 16 years. He was able to use a quad cane for mobility in his home and only used the wheelchair outside his home. The woman had used a wheelchair for five years and used the wheelchair full time for mobility inside and outside her home.

#### **Table of Acceptance Categories**

In order to outline the acceptance categories of wheelchair use, a table has been created. Table one outlines each acceptance category, stating participants in the category, mobility categories, and environment of wheelchair use.

**Table 1****Participant Characteristics in Wheelchair Acceptance Categories**

	<b>Reluctant Acceptance</b>	<b>Grateful Acceptance</b>	<b>Internal Acceptance</b>
<b>Participants</b>	Mr. C.D. Mr. K.L. Mr. O.P. Mr. S.T.	Mr. A.B. Mr. I.J. Mr. M.N. Mrs. Q.R.	Mr. E.F. Mrs. G.H.
<b>Mobility Without Wheelchair</b>	All participants able to walk in home using quad cane. One participant able to walk outside very short distances with quad cane.	Two participants able to walk in home with quad cane or mobility walker but had to use wheelchair for any outside mobility needs. One participant used wheelchair for all mobility needs	One participant able to use quad cane in home but not outside. One participant used wheelchair for all mobility needs.
<b>Environment in which wheelchair used</b>	Three participants used the wheelchair inside and outside the home. One participant used the wheelchair outside the home only.	All participants used the wheelchair inside and outside the home.	One participant used the wheelchair inside and outside the home. One participant used the wheelchair outside the home only.

**Perceptions Regarding Practicality of the Wheelchair**

The views of the wheelchair that the participants held and the acceptance category they had of wheelchair use were formed through many years of day to day use. The view of the wheelchair expressed was always accompanied by the participants talking about the practicality of daily wheelchair use. These practical issues are discussed below.

**Participants in all three acceptance categories could identify positive and negative aspects of wheelchair use. These practical issues of day to day wheelchair use were expressed by the majority of participants with emphasis varying among the participants. These benefits and others will be looked at in more depth when discussing meaning of wheelchair use among the participants so will not be expounded upon here, however, for increased understanding some are mentioned.**

**Benefits expressed by participants included the opportunity to be mobile, to be less dependent on others, to continue with previous activities, provided comfortable seating, accommodated for decreased energy and endurance, provided a sense of security, increased confidence in mobility, decreased loneliness due to increased mobility, and provided an opportunity for exercise if self propelling. Referring to the wheelchair, a participant who used a manual wheelchair for mobility within his apartment building expressed the benefits of wheelchair use in this way:**

**...It makes my life easier to get around. I can go downstairs, visit my friends. I just jump in it, and pull myself. The wife, if she's not home, then I pull myself across, and I'll tell her to leave the door open and I'll go down the elevator, go downstairs and visit my friends, come back upstairs, no problem (Mr. A.B.).**

**One participant who used the wheelchair for full time mobility spoke of its usefulness and necessity in her daily life:**

**Many mornings when I'm up the first thing is I use my commode and from there to the wheelchair and then wheeled out to the dining table and have my breakfast. And after that another homecare nurse comes and she finds me in the wheelchair and she brings**

me back and tidy me. And then after she's finished with me then she wheels back out in the living room and I'll stay there. I'll sit there and wait until it's lunch time and that's it. The wheelchair is my seat because the other chairs in the house.....I do sit in my rocker sometimes for an hour or so.... but the main place that I sit is the wheelchair (Mrs. G.H.).

On the negative side, ideas were expressed that the wheelchair was seen as confining, or a hindrance, or a bother. Again, these ideas will be explored further in the section on meaning of wheelchair use. Negative aspects of wheelchair use can also be seen when one looks at barriers to community participation that will be discussed later on in this section. These barriers include such things as confined spaces and uneven sidewalks. Some of these negative aspects can be seen in the following excerpt from an interview when speaking of the wheelchair:

Mrs. Q.R.: It's a nuisance sometimes, I find. To get in and out of places and you get to some place with steps and then you're kind of thinking if you don't know if you can get in or out of the place.

Interviewer: Is it a nuisance in any other ways besides..

Mrs. Q.R.: Yeah, if I get in the car we have to take it apart to get it in the car.

The amount of effort required to self-propel the chair was mentioned by most participants and was seen as a definite downside to manual wheelchair use. Participants with reluctant acceptance and grateful acceptance of wheelchair use spoke a lot about the effort involved in propelling the wheelchair. Interestingly, those with internal acceptance of wheelchair use did not specifically mention the amount of effort required in propulsion,

although they certainly often required assistance with wheelchair propulsion.

In speaking of the amount of effort required and difficulties of the hemiplegic pattern of wheelchair mobility, one participant said: "... (the wheelchair's) pretty hard to control cause I only got the one foot and the one hand to work with. So you gotta kind of pull yourself with your foot, you know. So you can't control it" (Mr. A.B.). In comparing independent mobility without a wheelchair to life with a wheelchair, one participant said:

...there are a lot of things that are so simple. The pretty average person to do you wouldn't even think about it before. You know, it isn't until you get in a wheelchair that you realize that, uh, to do certain things is quite a bit of effort. You know, a nuisance. Enough to say in uncertain terms, 'Oh to hell with it. It isn't worth it', you know (Mr. S.T.).

When another participant was asked about any obstacles that he had to deal with on a daily basis he responded: "Well, right now, the point that with this chair I just can't get where I want to go, that's all. It's too hard a job. It's just overwhelming. Which puts me in a funk. I get very depressed, ornery." (Mr. K.L.).

Most participants found that indoor mobility with the wheelchair required a lot of effort but outdoor mobility required even more effort. Most participants could not be independently mobile outdoors due to the excessive amount of effort required for manual wheelchair propulsion. Instead, they had to rely on caregivers or others to push them when they wanted to engage in outdoor mobility.

### Changes Over Time in Perception of Wheelchair and Its Use

The views of wheelchairs presented above represent the participants' view of wheelchair use at the time of the interview. However, it was evident that participants' views of wheelchair use evolved or changed over time. While this was not a longitudinal study and thus could not examine actual change in one's view of the wheelchair and its use over time, the respondents did speak retrospectively on how they viewed the wheelchair initially, in addition to how they viewed it at the time of interview. Wheelchair use required adjustment as did living with impairments caused by the stroke. When speaking of getting used to using a wheelchair, one respondent said, "You gotta grow into it (laughing)" (Mr. E.F.).

Initially, most participants did not view the wheelchair negatively. Many spoke of recognizing the need for the wheelchair while they were in a rehabilitation hospital and of seeing other wheelchair users in the hospital which seemed to almost normalize wheelchair use. One stroke survivor, when speaking of his initial use of the wheelchair said this: "I got taken down at Riverdale January 29<sup>th</sup> roughly. And I was there four months and uh, looking at and seeing the people there uh, (wheelchair use) was a little easier to accept" (Mr. S.T.). The wheelchair was a necessity for him and he could accept that because he was in a similar situation to others as a wheelchair user while he was in hospital. Another participant expressed initial fear but then appreciation of the wheelchair for the mobility benefit:

I feel very fortunate. I've got ... I'm still able to move around. Portability. It's given me a whole lot more portability. I'm not afraid of anything. I was at the beginning. It was a new start... like reborn. A help for sure ... my cane and my chair. I thought I was going to be bedridden... or whatever. A useless piece of meat. That's the way you feel. Like you're up at a blank wall... you don't know what's on the other side of the wall and you

can't get through the wall either. It's a new ball game. Thank God I adjusted pretty good. I can see that a lot of people don't. They defeat themselves (Mr. E.F.).

It seems that though there was fear of the unknown initially, there was also acceptance of the wheelchair, as the alternative was immobility and there were many others in the rehabilitation hospital using wheelchairs also.

The transition from hospital to home was an important step in the process of becoming more aware of the impact of the wheelchair on day to day life. This transition often had the stroke survivor thinking less positively about the wheelchair and its use as the reality of being a wheelchair user in his/her own home set in. Stroke survivors spoke of physical changes that had to take place in their homes in order to accommodate the wheelchair and the increase in effort required to perform routine daily chores when using a wheelchair. Furniture had to be moved, new equipment, such as a ramp, was installed, and rooms were renovated. Activities of daily living that were so simple prior to the stroke and wheelchair use were now very time consuming, difficult, and required enormous amounts of energy. One participant spoke of the effort involved in getting a drink of water in his home when in a wheelchair:

Um, sometimes it's a lot of effort for what you... you're getting out of where you're going and what you're doing. You know. Like, uh, to give you an idea, even if I'm in the house in a wheelchair, uh, to walk out and take a glass out of the kitchen cupboard, pour myself a drink of water and walk back.... You don't even think of it. But when you're in a cart (wheelchair) you think about it because uh, of course, it isn't always aware of where the glasses is to everything else that can you get at the uh, tap easily enough without moving some stuff and so it's uh, a bigger problem (Mr. S.T.).

**It seems that for some participants, the transition home with the wheelchair caused them to recognize some of the difficulties of wheelchair use. However, benefits of easing immobility and the need for the wheelchair were also recognized, leading them to continue with an overall positive view of the wheelchair.**

**Two of the stroke survivors spoke of how their view of wheelchairs and those who used wheelchairs had changed from pre-stroke to post-stroke: One participant, in the grateful acceptance category of wheelchair use stated: "... before the wheelchair and I saw someone in a wheelchair I would say, 'Ah poor guy', or 'Poor woman'. But now that I use the wheelchair I feel that I have conquered my illness" (Mr. I.J.). This change in view of wheelchair and its use is expressed by another participant, who had reluctant acceptance of wheelchair use:**

**Before it was me (in the wheelchair) I would see somebody in a wheelchair and see the trouble they were having, well the caregiver. I didn't know it was a caregiver then. I didn't know that title, and I know I have said to myself, "I'd rather be dead". No, I wouldn't. This is an alternative (Mr. O.P.).**

**There was clearly a change in attitude, toward the wheelchair and what it means to use a wheelchair, in these stroke survivors as they became the person in the wheelchair. The need for and use of a wheelchair, although not preferred by these participants, altered their perception of what life held for a wheelchair user. Wheelchair use was seen in a more positive light as it was experienced personally.**

**Perceptions of the wheelchair and its use clearly changed over time for the participants. This occurred from the onset of the need for a wheelchair to the time of interview and evolved from hospital to home and community.**

## Coping Resources

Continuity theory suggests that people adapt to aging in two major ways: by gradual, routine adaptation, and by mobilizing coping skills and resources to deal with crises.

Adaptation, according to Continuity Theory, is the process of adjusting oneself to fit a situation or environment, while coping means contending with or attempting to overcome difficulty (Atchley, 1999). The advent of the stroke and the need for a wheelchair brought about many physical, mental, and emotional changes for the stroke survivor. These changes required the use of coping resources to aid in adaptation and adjustment.

When examining coping resources with regards to acceptance categories, overall one does notice some differences. Table two outlines wheelchair use acceptance categories with coping resources mentioned by the participants in these categories. Numbers indicate the number of participants in that acceptance category who specifically mentioned, or showed evidence of, that coping resource in the context to adjusting to the stroke and/or wheelchair use. It is possible that other coping resources were present with the participants. This study did not specifically ask participants to list coping resources. These resources were mentioned by the participants when discussing adaptation to wheelchair use and related questions.

**Table 2****Coping Resources and Acceptance Categories**

<b>Coping Resources</b>	<b>Reluctant Acceptance</b> (n=4)	<b>Grateful Acceptance</b> (n=4)	<b>Internal Acceptance</b> (n=2)
Family Support	2	3	1
Positive Attitude	2	3	2
Religiousness	1	4	1
Perseverance	2	2	1
Community Support Groups	3	4	1
Being as Active as Possible	3	2	1

From this table one can see that each coping resource was seen in each acceptance category. As a group, proportionally, the grateful acceptance category appears to have the most coping resources. Religiousness and community support groups were coping resources for every participant in the grateful acceptance category, as was positive attitude for the internal acceptance category participants. No other coping resource was found for every participant in the categories. As a whole, coping resources does not have a clear association with wheelchair use acceptance categories. It is possible that some coping resources are more helpful or powerful than others. For example, positive attitude was seen in two of the four of the participants in the reluctant acceptance category, however, it was seen in three of the four of those with grateful acceptance of wheelchair use and both of those with internal acceptance of wheelchair use.

### Views of Powered Mobility and Its Use

As mentioned, two of the stroke survivors owned and used powered mobility devices in addition to owning and using manual wheelchairs. One participant used a scooter and one used a power wheelchair. In placing the view of powered mobility users on the graph, it would seem that both participants viewed the powered mobility device as a great asset. They could be put in the grateful acceptance category. However, it differed from the manual wheelchair users grateful acceptance in that these powered mobility users did not seem to also consider the device a necessity. It seemed to be viewed as more of a luxury item. The manual wheelchair appeared to be the necessity for them. While the powered mobility was part of the daily lives of these gentlemen, it seemed that they viewed the device as primarily a method of transportation outside the home, almost as they might have previously viewed a car. The lack of inside mobility could partially explain why the device was not viewed as a necessity or as a part of themselves. One of the participants spoke of the need for manual and powered mobility: "...what I'm really getting at, there were two aspects. If you had to get outside you need an electric (powered mobility device) and if you're inside you need a ... the other (manual wheelchair)" (Mr. S.T.).

Both participants spoke extremely positively about their power mobility devices. They spoke of the benefits of the devices and the increased freedom and independence that these devices brought. Speaking of the decreased dependence on others and the increased radius of mobility, the one power wheelchair user expressed his thoughts this way:

Sometimes my son would take me out, uh, in the cart but, uh, after a while I think it's a little boring. You know, he means well but there's not much to see because you're

confined enough where you go. Now the electric chair you got, if it's a pretty good one, uh, at the place they say depending upon where it's driven and the weight of the person, uh, on a charge of the batteries it would take you 25 miles. That's quite a distance. You know. I'd hate to have to ask my son to push me 25 miles! (Laughing) (Mr. S.T.).

Other benefits of the power mobility device included decreased effort required to attain mobility and increased community access. Although both gentlemen could identify some negatives aspects of the usage of power mobility devices, such as inability to transport the device in the car, finding maneuverability difficult in confined spaces, and non-use of the device in the home, overall they were extremely pleased with the device and its usefulness.

Interestingly, both gentlemen had pursued power mobility on their own, with no input from a therapist. The gentleman with the power wheelchair accessed a provincial funding agency for financing the wheelchair, and the chair was then prescribed by a therapist. The other gentleman said that he did not know scooters existed until he saw others with scooters and decided that he would like one himself and so went out and bought one from a local medical equipment vendor with no input from a therapist.

Of the eight remaining participants who did not use powered mobility devices, only one had a desire to purchase one. Unfortunately, this gentleman was deemed by his wife and previous therapists to be unable to appropriately and safely handle powered mobility due to his perceptual deficits and difficulties with judgment. He could predict the benefits of power wheelchair use, recognizing the decreased effort required, the increased distance he could travel with it, and the renewed roles, such as shopping, that he could fulfill if he had the improved mobility:

**(With a power wheelchair) I'd be more mobile, more, more... Things would be more accessible too. Like if I wanted to buy a pair of shoes, I'd go out and buy them. Now, I've got to pull myself into the car, my wife has to fold up the chair and put it in the car with me, put my leg in..." ( Mr. K.L.).**

**He asked many questions of the interviewer regarding powered mobility when he discovered she was an occupational therapist and knew much about wheelchair prescription, products, and usage.**

**When other participants who did not use powered mobility devices were asked why they did not use or desire a power wheelchair or scooter, they gave a number of responses. Two participants could not see the benefit of using power while two others were afraid of breakdown and of the maintenance that would be required for upkeep. Four participants felt that they would be unable to handle the device, and one other felt that since the power wheelchair or scooter could not be easily transported in the car that it would be of limited benefit to them. Interestingly, except for the last concern about transporting the wheelchair in the car, none of these fears brought forward by non-power device users were mentioned by the two participants who actually used the devices.**

## **Chapter Five: Results**

### **Meanings of Wheelchair Use**

Wheelchair use to the elderly stroke survivors in this study meant: increased mobility, increased independence and increased dependence, freedom and confinement, decreased spontaneity, and varied social response, and loss of some valued activities. Table three lists these meanings, showing which were found in each of the three acceptance categories of wheelchair use. It can be seen that increased mobility and varied social response were seen similarly in all three acceptance categories. Independence and dependence were seen in all acceptance categories but with differing emphasis. Freedom / confinement was not seen in the internal acceptance category of wheelchair use but was seen in the other two categories, with differing emphasis. Decreased spontaneity was mentioned by three participants, one in the reluctant acceptance category and two in the grateful acceptance category. Loss of some valued activities was seen in all categories but with frequency and contributing factors to loss differing with the three categories. These meanings will be discussed, in turn, below.

**Table 3****Meanings of Wheelchair Use and Acceptance Categories**

<b>Wheelchair Meaning</b>	<b>Reluctant Acceptance</b>	<b>Grateful Acceptance</b>	<b>Internal Acceptance</b>
<b>Increased Mobility</b>	<b>Yes</b>	<b>Yes</b>	<b>Yes</b>
<b>Independence / Dependence</b>	<b>More dependence than independence mentioned</b>	<b>Equal categories of independence and dependence mentioned</b>	<b>More independence than dependence mentioned</b>
<b>Freedom / Confinement</b>	<b>More confinement mentioned</b>	<b>More freedom mentioned (except for one participant who was blind)</b>	<b>Not mentioned</b>
<b>Decreased Spontaneity</b>	<b>Mentioned by one participant</b>	<b>Mentioned by two participants</b>	<b>Not mentioned</b>
<b>Varied Social Response</b>	<b>Yes</b>	<b>Yes</b>	<b>Yes</b>
<b>Loss of Some Valued Activities</b>	<b>Yes - participants mentioned losses a lot</b>	<b>Yes - participants mentioned losses less frequently</b>	<b>Yes - but attributed more to stroke than use of wheelchair</b>

**Increased Mobility**

The wheelchair allowed all participants increased mobility, which was highly valued. For participants in all acceptance categories, the use of the wheelchair meant that they had increased their mobility within and/or outside their homes. It is interesting that none of the participants was driving a car although most had driven previously. All were dependent on a spouse or family member and/or disabled transit for transportation within the city. This factor may have increased the appreciation of the wheelchair, especially appreciation for the powered mobility device.

The importance of mobility to human existence cannot be understated. All participants in this study valued mobility highly. One participant expressed the importance of mobility to him in this way: "Cause once your mobility is affected you feel like you're a dead person. This gives me an opportunity to still move. I'm not that dead yet. I'm still above ground. I've slowed down a bit but that's okay" (Mr. E.F.). Mobility, at least to this participant, meant life. Being capable of moving around, even if it was at a slower pace, was extremely important to all participants.

Using the wheelchair meant mobility to do things inside and outside the house in spite of physical deficits. When participants spoke about the increased mobility that the wheelchair brought, they spoke of it as a substitution for their mobility deficits. This can be seen in the following: "...But I couldn't do very much but, you know, it's limited. So that's, uh, where the wheelchair would come in allowing me to get around to do these things" (Mr. S.T.). Another participant spoke of the wheelchair giving mobility, despite deficits, in this way:

Most important thing, as I said before, it gave me an extra leg... gave me a little more strength, confidence to move about, to be more mobile. Not bedridden at home. Not in a bed looking out. I mean it's not easy but it's getting easier. I'm adjusting to it (Mr. E.F.).

The two participants with power mobility spoke of the improved outdoor mobility with these devices. Although the manual wheelchair increased outdoor mobility, it did not compare with the amount and type of mobility that the power device offered. One participant who used manual and power mobility devices spoke of his increased mobility with both devices:

That made a big difference being able to get around and get the paper. Do things. And

now, uh, when I go up there to Gravenhurst and if I hadn't had the electric I would have been stuck inside. But it allowed me to get out and do things, take a ride when I want to do and go out (Mr. S.T.).

For five participants, the use of the wheelchair meant that they could continue with the long distance travel to which they had been accustomed. For two participants it meant that they could continue to visit a homeland. For another it meant travel within North America. This participant expressed the benefits of wheelchair use for long distance travel in this way:

I'm able to go anywhere just about. I don't worry about it. We went to the West coast.

We're going to go to the East coast this summer. My kids gonna take me. I'm fortunate.

I'm not stuck, in other words. That's the biggest ... I'm still portable (Mr. E.F.).

Overall, the wheelchair increased mobility within the home, the community, and travel within and outside of Canada.

### Independence/Dependence

Wheelchair use to participants meant a mixture of increased independence and increased dependence depending on the circumstances and environment. Many participants felt that the use of the wheelchair meant that they were more independent and not as dependent on others as they would be otherwise, while many other participants spoke about the increased dependency on others that the wheelchair brought. Those with reluctant acceptance of wheelchair use emphasized dependence factors. Those with grateful acceptance spoke equally about independence and dependence factors and those with internal acceptance spoke more about independence than dependence with the wheelchair.

**The wheelchair allowed many participants to be independent in mobility inside their homes. These participants either were not able to walk or needed assistance to walk with a cane or walker. The wheelchair then, provided the opportunity for independent mobility in the home. For only two participants, the wheelchair allowed independence, although limited, mobility outside their homes. Disabled transit also allowed increased independence with the wheelchair outside the home and for some an opportunity to get out of the house without the caregiver. This would not have been possible without the wheelchair. When speaking of how life would be different if he did not have the wheelchair, one participant said: “Yes, I think I would have to rely on, uh, friends to take me where Wheeltrans take me now. I would have to rely on friends more. And my family would take me around” (Mr. I.J.).**

**Wheelchair use to a few participants meant the opportunity to lessen the burden on a spouse and was expressed by one participant in this way: “I’m not a hindrance, let’s say. I’m not a burden to anybody. The wheelchair accepts that burden. Not my wife” (laughing) (Mr. E.F.). Another participant stated: “...and it’s my only means of helping (spouse) cope with what I’ve got. Get in it (the wheelchair) and get on with it”(Mr. O.P.). Clearly, in these cases, wheelchair use meant less reliance on others, which was important for the participants. In these cases, one might argue that wheelchair use did not necessarily mean independence as it did less dependence.**

**In many cases, especially for those in the reluctant acceptance category of wheelchair use, participants mentioned the increased tasks and responsibilities of their caregivers and their dependence on them because of wheelchair use. Participants were dependent on caregivers for assistance with self-care activities that were often complicated by wheelchair use. For example,**

transfers in and out of wheelchairs were frequent during self-care activities. Dependence increased because of additional tasks specific to wheelchair use, such as pushing the manual wheelchair, making arrangements with Wheeltrans for pick up and delivery, putting wheelchairs in and out of the trunk, opening non-automated doors, and arranging for home modifications for improved wheelchair mobility in the home. Difficulties with maneuvering and pushing the wheelchair led all participants to rely on caregivers for outdoor mobility in the manual wheelchair. One participant explained why his wife had to accompany him on any outdoor mobility, "I don't go out alone. I don't think I trust myself alone to drive it around. I don't think I would get back" (Mr. O.P.).

### Freedom/Confinement

Participants expressed feelings of freedom and confinement with wheelchair use. Those in the reluctant acceptance category felt overall that the wheelchair was confining. Those in the grateful acceptance category expressed feelings of freedom that the wheelchair brought. One exception in this group was a participant who was blind and thus very limited in independent wheelchair mobility. Participants in the internal acceptance category did not specifically speak about freedom or confinement.

An example of expressed freedom that participants felt when they used the wheelchair is stated below:

Well..... I don't know what I would do without it (the wheelchair). I'd be lost without it. You need a wheelchair - it makes you free-er. Free to do things, you know. You know, you can go shopping, you can wheel yourself around in the summer time. You can

**wheel yourself outside and sit outside. Wheel yourself outside in the nice sunshine and that, you know? Makes you feel good” (Mr. A.B.).**

**The wheelchair for three participants allowed freedom to do things that they wanted to do, when they wanted to do it. This meant that they felt more in control of their lives.**

**The wheelchair to three participants meant freedom while to five others it meant feeling confined. These participants did not feel freedom in using the wheelchair. They spoke of the effort involved in wheelchair propulsion, limiting them in activities. One such participant voiced the concern about feeling confined: “I get confined. Um, sometimes it’s a lot of effort for what you.... you’re getting out of where you’re going and what you’re doing” (Mr. S.T.). And another such participant expressed it this way, “I don’t feel that freedom of movement I had when I wasn’t in the wheelchair” (Mr. I.J.). When speaking of how the wheelchair made him feel differently about himself, one participant spoke of lost freedom:**

**Mr. C.D.: Well, I don’t know I ...not much change in myself except lost freedom. Lost freedom.**

**Interviewer: You lost freedom to do what?**

**Mr. C.D.: Go to the garden and plant something ...or go fishing.. drive a car or anything. The same participant also spoke of feeling like he was under ‘home arrest’. He felt that he was imprisoned in his home. Interestingly, this same gentleman acknowledged the increased mobility possible with wheelchair use. In speaking of how things would be different for him if he did not have a wheelchair, he said, “Oh well, then I’d be bound right at home and no where else. I couldn’t go to (the) supermarket because I just don’t have enough energy to walk around” (Mr. C.D.).**

For all participants, the wheelchair was a reality of their everyday lives since the stroke. Few felt an increased freedom with the wheelchair while many felt confined and felt less free to move around and participate in activities that they at one time enjoyed. Those with reluctant acceptance mentioned confinement more often, whereas those in the grateful acceptance mentioned freedom more often. Those with internal acceptance of wheelchair use did not mention freedom or confinement.

### Decreased Spontaneity

Three participants spoke of the fact that they could no longer do things on a spontaneous basis. Everything needed to be planned ahead of time due to the use of the wheelchair, increased time and effort for participation in activity, and altered bodily functions, such as elimination. Outings needed to be planned ahead of time, from beginning to end. Often disabled transit, which usually requires at least a day notice, needed to be arranged, caregivers needed to have time to ready the participant for the outing as well as accompany them on most outings. Wheelchair accessible washrooms and other facilities had to be confirmed as being available and timing due to fatigue factors had to be taken into account. All these factors added together to produce the need to carefully plan outings and activities. This decreased spontaneity was mentioned by one participant in the reluctant acceptance category, and by two participants in the grateful acceptance category. Neither of the participants in the internal acceptance category mentioned this.

One participant who spoke of his life being less spontaneous as well as somewhat restrictive, said, "Well, it's a more circumscribed life 'cause I don't really go to places that I

would have gone to" ( Mr. I.J.). The same participant spoke later about how his life was different since he had to use the wheelchair and said, "Well, before the wheelchair I would say, 'Well, I'm going down here', or ' I'm going out here'. But now I have to change that to 'Can I go to such and such a place?' (Mr. I.J.). Another participant spoke of this loss of spontaneity: "I miss the ability to go where I want when I want. I was never still" (Mrs. Q.R.). There had to be consideration and thought put into participating in out of home activities. Spontaneity in community participation no longer existed in the lives of most of the participants, although only three participants specifically mentioned it.

### Varied Social Response

Society response to these elderly stroke survivors who were using wheelchairs was seen to be varied, however all participants felt that wheelchair use was socially acceptable and was not stigmatizing. Participants in all three wheelchair use acceptance categories spoke similarly about social response. To organize the responses and clarify understanding, this section will be divided into three main sections: Responses of family, Responses of friends, and Responses of the general public.

#### Responses of family.

The majority of participants thought that their family members, including children and spouses, treated them very kindly and appropriately and were very supportive. Family members were said to have provided excellent physical and emotional help to adaptation to wheelchair use and ongoing support in their daily lives. Wheelchair use, in spite of the difficulties it brought to family life, seemed to be generally acceptable and usually generated increased

kindness and consideration from family members. One participant spoke of increased attention from his daughters in this way: "My daughters (voice breaking) I think, I'll probably get in trouble for this, but my daughters are particularly kind to me and I sometimes think that they are trying to outdo the other. They are very good to me" (Mr. I.J.). This participant elaborated further later by saying that his daughters actually seemed to be competing among each other regarding who would take their father out on various outings. This type of extra attention by family members was not viewed negatively or seen as patronizing by any of the participants but was appreciated.

One participant felt that her family maybe felt sorry for themselves due to the amount of care she needed as seen in this dialogue:

Mrs. Q.R.: I guess they're a little sorry for you, in a way. They're sorry for themselves, I don't know.

Interviewer: Why do you say that, 'sorry for themselves'?

Mrs. Q.R.: Well, it's quite a lot of care you have to give a person like me.

This woman appeared to think that her losses and need for a wheelchair was viewed by her family as causing a burden and prompted some self pity among family members. This thought was in the minority as most participants only spoke positively of the response and support of family members.

#### Responses of friends.

Responses from friends to wheelchair use was also viewed to be positive for the most part. 'Friends' were people who had long-time contact with a participant but were also newer acquaintances that were acquired more recently, sometimes after the stroke event.

Five participants spoke of friends and acquaintances through their religious affiliations. Responses from friends at places of worship was seen to be 'splendid', very supportive, and much appreciated. These participants spoke of ministers, rabbis, and church friends coming to their homes, delivering written sermons to the home, and sending cards. When visiting these places of worship there would be many offers of help to navigate steps, and negotiate aisles. These reactions were seen as 'considerate' by participants. Two participants actually spoke of receiving special recognition in their places of worship due to their present health status and ability to attend the service. Again this was viewed in a positive light.

One participant spoke of being unduly nervous and apprehensive the first time he was to see his friends since using the wheelchair:

Mr. M.N.: ...But it did bother me the first time I went to some friends in the wheelchair.

Interviewer: And why did it bother you Mr. M.N.?

Mr. M.N.: I was self-conscious being in a wheelchair.

Interviewer: How do you feel people reacted to you in the wheelchair:

Mr. M.N.: Perfectly normally. They didn't make a fuss.

Interviewer: Did that make you feel any better about it?

Mr. M.N.: No. I got accustomed to it really.

In spite of initial apprehension of having friends see them in a wheelchair, most participants felt that friends treated them very well, generally as no different than prior to wheelchair use.

Two participants did mention that they felt that their friends felt sorry for them when they thought of what they were capable of previously. One gentleman spoke of this in this way:

People feel sorry , you know, especially if they know what I was before and they know

what I am now. They feel sorry for me. I can feel it, I can feel it in their tone of voice, you know. That's ..... But I don't want nobody to feel sorry for me. Because, because there's , there's some people way worse than me. So why should any people feel sorry for me? I got my, my sense, I got my mind. My mind is working okay (Mr. A.B.).

One participant also felt that friends felt sorry for her and actually avoided her because of the need for a wheelchair: "Some people don't like to come cause you're in a wheelchair. They don't like to see you in a wheelchair. So they say, 'Well, you know, I'll wait 'til you're....'. But see this is three years in September for me, so it doesn't come easy" (Mrs. Q.R.). This woman felt that her wheelchair use made her friends uncomfortable so they avoided coming to see her. Most participants did not voice this thought of avoidance on the part of friends.

Many participants had made new friends at support groups that they attended. The friends attending these groups also had some type of disability. Reaction from these friends to wheelchair use by the participant was always viewed to be positive and supportive.

Generally, responses of friends and acquaintances to wheelchair use was seen as positive. Most felt that they were treated kindly and generally as they were prior to wheelchair use. Only two participants felt that their friends felt sorry for them and/or avoided them because of wheelchair use. It should be noted, however, that many participants spoke of the death of some or many of their friends, stating that they had fewer friends than previously.

#### Responses of the general public.

The majority of the participants felt that the general public was kind and helpful towards them as wheelchair users. Many mentioned that they felt that wheelchair use was now more acceptable than it had been previously and attributed this to increased education of disability and

increased exposure to those with disabilities. One participant actually said: "There's no stigma attached to being in a wheelchair" (Mr. M.N.). This was the feeling of most participants. Some participants felt that people 'felt sorry' for them or were 'ignorant' or 'nosey', and some felt that people were overly helpful, to a fault. One gentleman, when asked how people reacted to him in a wheelchair said: "...Kindly, mostly. Patronizing some. Little kids, scared to death" (Mr. O.P.). The positive and negative responses from the general public will be discussed further in the paragraphs below.

Most participants spoke of the kindness of the general public when out in the community. One participant said, "...on the whole, I think the public is probably a lot more aware of helping than they used to be" (Mr. S.T.). They spoke of offers to hold doors, help with maneuvering the wheelchair up a curb, stopping traffic as required, etcetera. A few thought there was increased awareness of helping those with disabilities due to increased publicity and an increase in elderly people who are active. Two participants who were involved in long distance travel mentioned that Toronto was better than other cities in the world when comparing general public attitude towards those in wheelchairs and wheelchair compatible facilities.

It appears that there are times when people don't know whether they should help or not, as evidenced in the comments of one participant when asked how people treated him in the wheelchair: "Mostly kind. Not sure what to do or whether to interfere. I let (spouse) take over most times. But generally they're kind" (Mr. O.P.).

One participant found that people were 'nosey' (Mr. A.B.). They looked at him when he was in the wheelchair in a way that he found displeasing. However, another participant stated that people generally didn't look at him at first and he found this unpleasant. Obviously,

responses of the general public in terms of eye contact and interpretations of such responses from the participants varied.

A few participants mentioned that they would receive special treatment when in their wheelchair in the community. One participant gave an example of this special treatment: "...They see you in a wheelchair, they move you up or do something like that" (Mrs. Q.R.). Another participant who handed out religious magazines compared this practice before and after using a wheelchair:

"I'll place (the religious magazines) on the street as I meet people. And what I find, uh, is that they accept more literature off me now than when before I got the stroke. Because I think they feel sorry for me. Probably" (Mr. A.B.).

This sensation of people feeling sorry for the participants was mentioned only by this participant when speaking of the general public. Others only spoke of it with regards to family or friends.

One of the participants that used powered mobility said that often people in his apartment building would often comment on his scooter when they greeted him. This annoyed him: "(they would say) 'How are you doing Mr. A.B.? Your wheelchair working good? (Laughing) It looks like it's working good (Laughing). A bunch of dummies! What a question! They can see that it's working okay! Oh dear me!'" (Mr. A.B.). Often these same people would call this gentleman's scooter, a Cadillac. Again, he found this annoying.

A few participants spoke of feeling in the way, due to taking up too much space in an elevator with a wheelchair, or being too slow in a store aisle. One participant said she felt like a 'humbug'. This same participant, when asked how people reacted to her in a wheelchair, responded:

I've never seen any reaction. Never. Except I'm in the way or so. Like on the elevator or so. People will be coming in with strollers with the babies and I'm, well, I have to wait on someone to straighten me out and vie them the way to come in. That, I noticed that a couple of times. Like I was in the way (Mrs. G.H.).

Participants felt like people seemed to be in a hurry and seemed annoyed by someone in a wheelchair who impeded their progress or slowed them down in some way. These participants spoke of feeling in the way, and spoke of some people not holding a door or cutting in front of them, with most attributing this to people being in a hurry, rather than to a specific reaction to someone in a wheelchair.

#### Loss of Some Valued Activities

Wheelchair use provided increased mobility therefore participants were able to do many activities that they otherwise could not do. However, use of the wheelchair also meant loss of some activities that participants engaged in prior to the need for a wheelchair. Certainly, participants had to deal with many losses since their strokes and did speak of these losses. However, they also spoke specifically about losses related to wheelchair use. These losses were due to environmental barriers or to the amount of effort required by the stroke survivor and/or the caregiver. Those participants with reluctant acceptance of wheelchair use spoke a lot about losses, attributing them to the stroke and to wheelchair use. Participants with grateful acceptance of wheelchair use spoke about these losses also, but to a lesser extent than those with reluctant acceptance. They also attributed the losses both to the stroke and wheelchair use. Those with internal acceptance of wheelchair use also spoke of losses of valued activities but

attributed them more to the stroke than to wheelchair use.

Wheelchair use to all participants meant a loss of some valued activities, although some spoke of these losses more than others. These losses often related to environmental barriers. They included: going to the cottage, going to places of worship, visiting the homes of family and friends, gardening, vacationing in other countries, and attending bridge club. One participant spoke very sadly of his loss of spending time at his cottage where he loved to boat and fish and spend time: "...I've never been no place except the cottage, except my cottage with the wheelchair. But I hated it so much , I sold the cottage and I sold the car. I sold everything" (Mr. A.B.). Another participant spoke of the fact that she could no longer attend her church: "I don't get to my church because it's not wheelchair accessible. And I was a church woman. I was president of my UCW and all that stuff. I was in church work for many years. But I can't get to it" (Mrs. Q.R.).

Sometimes the participants were able to engage in activities but not as frequently due to effort or time involved or help needed. Participants spoke of shopping and going to the movies less, activities that they previously enjoyed and spent much time doing. When asked about activities that she previously liked to do that she did not do now, one participant replied: "Well (I haven't gone) for a long, long, time. To go to the mall I need someone with me to wheel me around to see what's there. And then I can choose anything that I would like. But I must have someone" (Mrs. G.H.). This woman's husband was unable to take her out due to his own medical condition, being unable to lift and push the wheelchair as required. Homecare provided personal care but did not have time to accompany the participant out shopping.

Due to environmental barriers, effort required, and dependency issues, wheelchair use to

the participants, meant loss or decreased frequency of involvement in valued activities. It would be thought that self-image and self-identity were challenged by this loss of activities.

Interestingly, most participants said that the stroke and the need for the wheelchair had not changed how they viewed themselves. They could identify areas in their lives and characteristics that had changed and those that had remained consistent but said that they still viewed themselves in the same way as prior to wheelchair use. Among the characteristics that participants said had not changed were: the presence of a sense of humour, the tendency to be a loner, being determined or a fighter, being laid back, or caring, considerate, or helpful.

Examples of characteristics that had changed were: being an active sports participant, being a perfectionist, feeling independent. Even amidst these changes, most participants did not view themselves differently than prior to the stroke and need for the wheelchair. One participant did say that she felt that she was a different person since the onset of the stroke. She had been extremely active, participating in many community activities but now said that she tries not to be too much trouble. She had reverted to a passive role in her family and community. One participant, with grateful acceptance of wheelchair use, referred to himself as a 'cripple' three times in the interview (Mr. A.B.) and one participant, with reluctant acceptance of wheelchair use, when asked to describe himself said he was an 'old man in a wheelchair' (Mr. C.D.).

Identity would seem to be altered for these participants even if they did not see that themselves.

## **Chapter Six: Results**

### **Impact on Community Participation**

As presented in the previous chapter, wheelchair use for all participants, meant increased mobility both within and outside their home environments but also meant a loss of some valued activities. This chapter speaks to these two meanings, relating them to the impact of wheelchair use on community participation.

The wheelchair was seen as an enabler for participation in the community. However, the difficulties of using a wheelchair in the community were also noted. Participants spoke of many problems and considerations when accessing the community and participating in various community activities. All of the participants, due to their mobility deficits, acknowledged the role of the wheelchair in increasing the opportunity for community participation. One participant, when asked how things would be different for him if he did not have a wheelchair, replied: "Oh well, then I'd be bound right at home and no where else. I couldn't go to (the) supermarket because I just don't have enough energy to walk around" (Mr. C.D.). Another participant echoed these same thoughts: "I'm thankful that I got it. I don't have to stop to go to be outside. To go out somewhere" (Mr. E.F.).

Certainly the use of a wheelchair affects community participation as compared to the category of participation prior to the stroke and the need for wheelchair. This change in community participation pre and post wheelchair use was expressed in this way by one stroke survivor: "Well, before the wheelchair I would say, 'Well, I'm going down here' or 'I'm going out here'. But now I have to change that to ... 'Can I go to such and such a place?'" (Mr. I.J.).

Except when specifically mentioned, participants in all wheelchair use acceptance categories were found to be similar in their expression of types of community participation and barriers and facilitators of participation.

The next section will present the types of community participation in which the participants in this study engaged. Following this, barriers and facilitators of community participation will be presented based on the ICIDH-2 model, looking in turn at impairment in body function and structure, activity limitations including dependence, and contextual factors. The impact of powered mobility devices on community participation will also be discussed.

### Types of Community Participation

Participants were out of the house with their wheelchairs from one to seven times per week. They tended to go out more in the summer rather than the winter and many did not venture out unless the weather was nice and clear. It was found that the participants accessed the community for various activities. Most were involved in leisure activities in the community such as Senior's Centres, visiting the racetrack, going to movies, and going to parties. Many also accessed the community to participate in religious activities such as attending services, and Bible studies. One participant handed out religious tracts in his community. Two were still involved in physiotherapy sessions and went to them on a weekly basis. A few would wheel around their community with no particular destination in mind. Many would accompany their caregivers on trips to the bank, grocery and department stores. It is noteworthy to mention that it was rare for a participant to visit family or friends in their homes even if they were within close proximity to the participant's home. The reason given for this was that the homes often

had stairs, bathrooms, or other small spaces which would make wheelchair mobility difficult or impossible. Visiting with family and friends usually occurred in the participant's own home where mobility issues had already been addressed and solved. Noteworthy also, is the fact that five participants spoke about travel outside the Greater Toronto area. Two traveled within Ontario and traveled by car and two traveled by plane outside the country and one traveled by car outside the county. So half of the participants were involved on an infrequent basis in long distance travel. The purpose of this travel was either vacation or to visit a homeland.

### **Facilitators and Barriers**

Using the ICIDH-2 model, the factors affecting community participation in this study sample of elderly stroke survivors who are wheelchair users will be divided into three main areas: Impairments in body function and structure, Activity limitations including dependence factors, and Contextual Factors including environmental factors and personal factors. Dependence factors defined as reliance on others, would be an aspect of impairments in body function and structure according to ICIDH-2. However, while listed under the impairment area, they will be considered separately as these seemed to be a very important factor in considering and actually participating in the community. All factors will be discussed as they relate to wheelchair use and as mentioned by the participants. These factors will be explained and discussed in turn.

#### **Impairments in body function and structure.**

Impairments in body function and structure are problems in the physiological or psychological functions of body systems or anatomical parts of the body that lead to significant

deviation or loss (WHO, 1999). In this study, impairments that impacted community participation were altered bodily functions such as urinary incontinence and frequency problems, decreased endurance or stamina, loss of function in arm and/or leg leading to problems with mobility, perceptual deficits, and physical discomfort when sitting for long periods. These impairments would be considered barriers to community participation.

The urinary problems and physical discomfort deficits are not often considered when speaking of barriers and facilitators of wheelchair users participation in the community. For the most part, one thinks of environmental barriers. However, these 'personal' barriers are very real issues for the elderly stroke survivor and must be dealt with on some category for community participation to be successful. One participant said he needed to "assess my body functions before we go anywhere" (Mr. K.L.). Wheelchair accessible washrooms were often not available or were problematic in some way. One participant mentioned that the wheelchair helped him with his deficits in this area as it allowed him to get to the washroom fast enough to avoid incontinence.

The mobility impairment and decreased endurance, stamina, and balance led to the need for a wheelchair. The wheelchair, in this way, was a facilitator for community participation. The wheelchair accommodated for the loss of function in the leg and for the deficits in endurance, balance, and stamina. Many participants, even though they could ambulate with a quad cane indoors, needed the wheelchair for community participation due to risk of falls when on uneven ground or in a crowded, hurried situation. When the participant had a comfortable cushion in the wheelchair, this also accommodated for the seating discomforts.

### **Activity limitations.**

**Activity Limitations are difficulties an individual may have in the performance of activities. An activity is limited when the individual, in the context of a health condition, either cannot perform the activity at all or has difficulty performing the activity in an expected manner (WHO, 1999). In this study, activity limitations lead to dependence issues, which played a large part in determining community participation. Due to activity limitations, the participants had to depend on caregivers to perform or help perform a variety of activities of daily living, as discussed previously. These dependence issues are discussed below.**

**Dependence issues include any need for care or service from others that the participant expressed. These dependence issues seemed to be extremely important factors for the study participants when considering community participation. The participants spoke of the availability of their caregivers, the effort required by them, and the actual ability of the caregivers when speaking of things to consider when venturing on any outing outside the home. These thoughts are expressed by one participant in this manner: “To go to the mall I need someone with me to wheel me around to see what’s there. And then I can choose anything that I would like. But I must have someone” (Mrs. G.H.). Another participant acknowledged the changes to his wife’s life when asked how often he actually got out of the house with the wheelchair: “No regularity. Just whenever we need to. As long as (spouse) is there and available I’m alright.... My life’s stopped alright but (spouse)’s stopped in a different way. The role of caregiving” (Mr. O.P.). The same participant clarified some of these caregiving responsibilities when considering community participation. He spoke of his wife having to**

push the wheelchair in the community and also the process of getting into the car to go somewhere: "...I get downstairs in the foyer, (spouse) brings the car to the front door and then we transfer me to the front with (spouse) in the passenger seat and (spouse puts the) wheelchair into the trunk of the car" (Mr. O.P.).

The participants were very conscious of the daily caregiving burden on their spouses, such as help with self-care and homemaking responsibilities, and often did not want to add further to that burden by requesting a visit into the community which would require more of the caregiver's time and energy. Many of the caregivers, being elderly, had compromised health themselves. Among the health difficulties of caregivers mentioned by participants were severe arthritis, recent knee replacements, and cataracts.

#### Contextual factors.

Contextual factors include environmental factors and personal factors that may have an impact on the individual with a health condition and that individual's functional state (WHO, 1999). Environmental factors are external to individuals and make up the physical, social and attitudinal environment in which people live and conduct their lives (WHO, 1999). Personal factors are features of an individual that are not part of a health condition or functional state. They include such things as age, race, gender, educational background, experiences, personality and character styles, social background, profession and past and current experience (WHO, 1999).

Environmental barriers were mentioned frequently by participants and included: heavy doors, narrow store aisles, crowded places, stairs, uneven sidewalks, rough ground such as potholes and grass, inaccessible washrooms, difficulties getting the wheelchair into the car, the

effort required to propel the wheelchair, declining health of caregiver, foul weather, poor fit of wheelchair to participant, and negative society response. Participants had comments such as the following: "...It's a nuisance sometimes, I find. To get in and out of places and you get to some place with steps and then you're kind of thinking if you don't know if you can get in or out of the place" (Mrs. Q.R.). Another participant commented:

...The walk there would be alright except for these sidewalks. They're awful. Terrible.

That's one comment to make about the sidewalks. Accessibility is generally very good in Richmond Hill. It's getting better. But there are some places just not accessible.

Don't even think about it" (Mr. O.P.).

Environmental facilitators for community participation mentioned by the participants were: elevators, automatic door openers, disabled parking spaces, wheelchair accessible transit systems, wheelchair accessible washrooms, ramps, the wheelchair's ability to fold, power mobility devices, availability of caregiver for outing, positive society response, and good fit of the wheelchair to the participant. One example of comments from participants in speaking of environmental facilitators:

...I go visiting my friends in the next building and they've installed the automatic door openers. So society's becoming more aware of the needs of the disabled. A lot of places have installed ramps and got automatic door openers and elevators. In my synagogue they installed an elevator (Mr. M.N.).

These lists of barriers and facilitators is surely not exhaustive when considering wheelchair use in the community. Participants were not specifically asked to list environmental barriers to community participation. These factors just came up in conversation but certainly

**impacted the ability of the participants to participate in the community.**

**Personal facilitators affecting community participation mentioned by the participants were psychosocial benefits of getting out of the house, a positive attitude or outlook that appreciates activity, and continuation of previous roles and activities or adoption of new roles and activities contributing to a sense of self-worth. One participant commented on the importance of a positive attitude, stating that you just have to 'get on with it' (Mr. O.P.), when speaking about life as a stroke survivor. Another participant said: "It's real important to keep yourself busy. Take your mind off your problems. I don't even think about my problems anymore" (Mr. E.F.). Examples of roles and activities that contribute to psychosocial well-being: "...wheel yourself outside in the nice sunshine and that, you know? Makes you feel good" (Mr. A.B.). One participant spoke of his volunteer work at a community centre group: "...I think I'm a good influence on some of them. It means a lot to me. It gives me courage to know that I'm doing something good" (Mr. E.F.).**

**Personal barriers for community participation for the study participants were the presence of other health conditions, lifestyle habits of inactivity, and past experiences in the community that were considered negative. There was only one participant that did not have any co-morbidities. Two of the participants had recent hip fractures, two had emphysema, many had hypertension, arthritis, and heart disease, and one was blind. Other personal characteristics such as age, gender, and financial status were not mentioned as factors in community participation.**

### **Activity Levels**

**Participants spoke generally about their activities prior to the stroke and need for the**

wheelchair. This was contrasted with their present activity level. Well being was construed by affect observed, comments made, and general tone of interview. Using the Continuity Theory activity levels, it was seen that all but one participant showed moderate activity decline. Three participants showed a decline in activity level with some offsets. Their overall activity level declined and they were not able to continue with some previously enjoyed activities. However, they partially offset those losses by engaging in new activities. Six participants could be categorized by having a moderate activity decline with continuity. They continued to engage in previously enjoyed activities but showed moderate losses in activities. In other words, their pattern remained the same but the level of activity declined. They did not offset their losses with new activities.

One participant showed disengagement, with a profound activity loss and no offsets. This had a severe negative effect on his well-being. The need for the wheelchair did not allow him to continue with his gardening, fishing, and other previously enjoyed activities. He spoke much of these losses.

It is interesting to compare acceptance category of wheelchair use to activity level. See Table 4 for this comparison.

**Table 4**

**Activity Levels and Acceptance Categories**

<b>Activity Level/ Activity Decline</b>	<b>Reluctant Acceptance n=4</b>	<b>Grateful Acceptance n=4</b>	<b>Internal Acceptance n=2</b>
<b>Disengagement (Profound Activity Decline)</b>	1	0	0
<b>Decline with Offsets (Moderate Activity Decline)</b>	2	1	0
<b>Decline with Continuity (Moderate Activity Decline)</b>	1	3	2

Those with reluctant acceptance of wheelchair use had moderate to profound activity decline. One participant had disengagement, with severe negative effect on his well-being. Two participants had decline with some offsets, one with severe negative effect on well-being, and one with mild to moderate negative effect on well-being. One participant had decline with continuity with mild to moderate negative effect on well-being.

All participants with grateful acceptance of wheelchair use showed moderate decline in activity level. Three participants showed decline with continuity, with mild to moderate negative effect on well-being. One participant showed decline with some offsets, with severe negative effect on well-being.

Both participants who accepted the wheelchair as a part of themselves, showed decline with continuity. These participants in this final grouping did not dwell on lost activities but

used the wheelchair to participate as much as able. One participant appeared to have mild to moderate negative effect on well-being, and the other participant appeared to have mild negative effect on well-being.

### Powered Mobility Devices as Facilitators

Power mobility devices were found to increase frequency of community participation. The use of these devices lessened the effects of impairment in body function and structure and decreased dependence on others. Manual wheelchair use required a lot of effort. The effort required either caused the participants to decide not to venture out into the community, to do so to a lesser extent, or to rely on others for wheelchair propulsion. The powered mobility devices decreased the effort required for mobility and thus for community participation. Expressing the amount of effort required in manual wheelchair use as compared with powered mobility, one participant said:

You got to have enough desire to, uh, want to do it. Yeah. And, uh, I can't say too much for the electric - it is in the same category. You know. But it ...the nice part of it is, uh, it isn't the effort that that if you're using your wheelchair (Mr. S.T.).

Power mobility users did speak of environmental barriers but these barriers seemed to negatively impact community participation to lesser degree. Sometimes, environmental barriers, such as hills and slopes, were overcome by the powered mobility device. One participant with a power wheelchair spoke of the difference the use of the chair made:

But up until then, uh, my difficulty is that with only one work, arm to work with, I couldn't even get up our driveway and our driveway is not slopey. And so, until I got

the electric cart I was limited (Mr. S.T.).

### **Summary**

The wheelchair, manual or power, was a definite enabler for community participation among the participants. However its use also created problems, such as limiting destinations and creating increased dependence on others. The wheelchair helped to overcome and lessen the impact of some impairments in body function and structure and activity limitations experienced by the participants. Dependence on others, in spite of, and sometimes because of, wheelchair use was a major factor for consideration of community participation. Environmental and personal factors were also important considerations in participating in the community. Powered mobility devices seemed to increase community participation due to the decreased effort required for mobility, the decreased dependence on others, and the ability of these devices to overcome some environmental barriers.

## **Chapter Seven: Discussion**

The purpose of this study was to investigate the views and meanings of wheelchair use in elderly stroke survivors who use a wheelchair in their home and community. The effect of wheelchair use on community participation was also investigated as it interacted with the views, meanings, and acceptance of wheelchair use in this population. This study contributes to the bodies of knowledge on emotional acceptance of assistive device use, stroke rehabilitation, and continuity theory.

Overall, the wheelchair, although viewed somewhat differently by the participants, was viewed positively. Three categories of wheelchair use acceptance was noted. Four participants had reluctant acceptance of the wheelchair, four participants had grateful acceptance of the wheelchair, and two participants had internalized acceptance of the wheelchair. In this study, the term 'category' has been used to define the participants' various acceptance of wheelchair use. 'Category' was deemed to be the best terminology as it implies a class or type of thing, in this case participant acceptance of wheelchair use. A term such as 'level', or 'stage' implies a progression and so would be inappropriate to use to describe wheelchair use acceptance in this study as it is unknown whether these acceptance categories are progressive or static.

Participants identified positive and negative aspects of wheelchair use and changes in their views of the wheelchair and its use over time and circumstances. Sample size was too small to draw conclusions but it was found that varied reliance on wheelchair for mobility needs and gender were not associated with acceptance category of wheelchair use, whereas length of time using wheelchair did seem to have some relationship with acceptance category of wheelchair use.

Wheelchair use, to the participants in this study, had various meanings. To all participants, wheelchair use meant increased mobility, varied social response, and loss of some valued activities. It also meant independence to some but also more dependence on others. It meant freedom but also a feeling of being more confined. Decreased spontaneity was mentioned by three participants. Different participants emphasized different meanings, with some meanings seemingly having more significance to the participant, than others.

Community participation was positively affected by wheelchair use in that it enabled the stroke survivor to venture beyond his/her home in spite of mobility deficits. Facilitators to participation in the community, aside from the wheelchair itself, were voiced by the participants. However, there were also a number of barriers to community participation about which the participants spoke, including issues surrounding body function and structure, activity limitation including dependence, and personal and environmental factors. Factors affecting community participation did not seem to differ significantly among the categories of wheelchair use acceptance.

This discussion section will be divided into two sections. The first section will compare and contrast findings from this study with findings of other research in the framework of Continuity Theory. Internal patterns, external patterns, and developmental goals will be discussed as pertaining to acceptance categories and meaning of wheelchair use. The second section will involve discussion of adaptive capacity and response. Activity patterns, including community participation will be discussed, considering the continuity/discontinuity occurring in this population of wheelchair users.

The onset of stroke, for the participants in this study, brought many discontinuities to

life, mobility deficits being one of them. The use of a wheelchair for all participants was a discontinuity in itself. All four dimensions of the stroke survivor's life were affected. Participants noted changes in internal and external patterns, and developmental goals, which required adaptation. The four dimensions, as outlined in continuity theory will be discussed in the sections below, as they relate to wheelchair use. The acceptance of wheelchair use, which incorporates the view of the wheelchair, the meanings of wheelchair use, and community participation, will be discussed as they were affected by, and contributed to issues of continuity and discontinuity in the lives of the participants. Continuity and discontinuity in activity categories will also be discussed. In this present study, it was somewhat difficult to precisely measure change in activity category as it was not a longitudinal study. Information regarding change in activity category could only be construed by analyzing comments by the participants, given retrospectively, on the effect of the wheelchair on overall activity category. From this information, it was possible to get a global picture of changes in activity categories pre and post wheelchair use. It is understood that many of the losses in activity category were due to the physical, cognitive, perceptual, and emotional effects of the stroke and not due to wheelchair use in itself. Activity category responses of the participants will be discussed later as they pertain to view of the wheelchair. Well-being was construed by affect observed, comments made, and general tone of interview.

#### Internal patterns

Internal patterns, such as self concept, attitudes, and values attributed to mobility and independence, contributed to the category of acceptance of wheelchair use, and the meanings associated with its use. Reciprocally, the stroke and need for a wheelchair for mobility affected

the self-concept of at least some of the participants. These effects will be discussed as they relate to acceptance categories and meanings of wheelchair use. According to continuity theory, people are motivated to maintain these inner mental constructs that represent a lifetime of selective investment (Atchley, 1999). Although much continuity was seen in the internal patterns of the participants in this study, changes were also evident.

Betsy Fife in her article, 'The Conceptualization of Meaning in Illness' (1994) states that meaning is predicated on an individual's specific cognitive response to a particular event. She goes on to state that meaning is integrally linked to identity (an aspect of internal patterns) and is the basis of continuity between past and present (for both internal and external patterns). This definition of meaning aids in understanding the variety of meanings of wheelchair use among the participants and ties in with continuity theory. As each participant has his/her own identity and cognitive response to using a wheelchair, s/he will respond in a unique way, in the context of his/her past life and activities.

Participants spoke of how their attitudes affected their adaptation to stroke and acceptance of wheelchair use. Participants spoke of 'just getting on with it', and 'accepting it', referring to adjusting and accepting wheelchair use. They spoke of life-long patterns of attitudes and values and how this affected wheelchair acceptance. Self-concept also appeared to have an effect on adaptation to stroke and wheelchair use. One participant spoke of being a 'fighter' and fighting the deficits the stroke brought. Another participant felt that adjustment to the wheelchair was easy compared to adjustments that had to be made due to the stroke. Others felt that they were 'determined' or 'a survivor'. It was evident by these descriptions of self used in the context of adaptation to the wheelchair, that the participants relied on self-concept and past

**experience with change to deal with the advent of wheelchair use.**

**Most participants in this present study, felt that they were the same person as prior to wheelchair use, even though some activities and roles had changed in their lives. They could identify characteristics that remained unchanged. In the context of the participant's self identity, the wheelchair meant different things based on how it contributed to and had an effect on the continuity of the internal patterns of his/her life, specifically how it affected self-image and self-identity.**

**When examining attitudes and descriptions of self or self-concept according to wheelchair acceptance categories, not much difference is noted. The only thing that stands out is the fact that of those that described themselves most negatively, two were in the reluctant acceptance category, and one was in the grateful acceptance category. Neither of the two participants in the internalized acceptance category described themselves in a negative way. It is possible that for the three participants with a more negative view of self this view also affected the view and acceptance category of the wheelchair. One of these participants was on medication for depression and was the participant who spent much time speaking of his desire for power mobility. This may have also affected his view and acceptance category of wheelchair use.**

**Previous research would lead one to believe that identity through social roles and self-identity had to be re-negotiated because community participation and activities became limited for these participants. Although participants recognized the limitations in activities and loss of social roles, most did not think that they had undergone a change in self-identity. It is possible that these participants had used a wheelchair long enough that the process of change in self-**

identity had occurred many years previous. They may have already incorporated the new self-image and considered this the new normal, causing them to place less emphasis on the re-negotiation process. It is also possible that for most of the elderly participants in this study, self-identity was well established and not challenged to as great an extent as it might be for some younger person confronted with the need for a wheelchair.

The value participants placed on mobility prior to stroke seemed to affect their view of wheelchair and acceptance of wheelchair use. All participants valued mobility highly but some were more content to be less mobile. To illustrate this point the circumstances of one participant is highlighted. The participant who spoke of his desire for a power mobility device was very frustrated with the difficulties in manual wheelchair propulsion. Prior to his stroke he was a truck driver, and loved to bike and hike. He valued mobility highly before the stroke and need for the wheelchair and was very frustrated with his present category of mobility. This led to a less positive view of the wheelchair and only reluctant acceptance of its use. The more the wheelchair helped the participant to approach their ideal mobility category, the more fully they accepted the wheelchair.

All participants were accepting of the wheelchair. The initial prejudice towards the wheelchair, seen in other studies studying mobility devices, was not observed in this study (Bates, Spencer, Young, & Rintala, 1993; Rush & Ouellet, 1997). Participants, speaking retrospectively about their initial wheelchair use, did not speak negatively about the wheelchair. Two participants, one with reluctant acceptance of wheelchair use and one with grateful acceptance of wheelchair use, spoke of their negative view of the wheelchair prior to their need for it, but contrasted that with the positive attitude that they now had. Their original prejudice

was obliterated by seeing the benefits of the wheelchair and understanding the alternative of not using the device. It is possible that the participants had forgotten about initial prejudice toward the wheelchair, however, this is unlikely as they could recall events surrounding the stroke event with good detail.

Rush and Ouellet (1997) found that perceived long-term, permanent need for the mobility device resulted in a more negative response to the device. This was not the case in this study, however. All participants needed and used the wheelchair on a daily basis and had relied on it for at least two years and viewed the device positively overall. It is possible that two of the participants did not think of the wheelchair as a permanent solution to their mobility problem. One participant spoke of his goal to walk again and get out of the wheelchair and another participant felt that she would continue to improve in her ambulation, but did not speak of giving up her wheelchair completely. Their acceptance of wheelchair use was reluctant. This would be in contrast to previous findings. The difference in previous study findings and the present study, can be explained by the fact that stroke is a sudden rather than a progressive disease, as found in the elderly participants in Rush and Ouellet's study. For the participants in this study, the wheelchair did not symbolize further decline, but enhanced mobility and an alternate to limited mobility that occurred as a result of the sudden onset stroke.

It is thought that emotional acceptance of the wheelchair occurs over years of use (Bates, Spencer, Young, & Rintala, 1993). Participants in this present study ranged from two to sixteen years of wheelchair use, with the mean years of use being 5.6 years. It is possible that emotional acceptance of the wheelchair took a number of years, with initial acceptance only being out of necessity. Those that saw the wheelchair as a necessity only, accepting wheelchair use

reluctantly, may not have the category of emotional acceptance of the device that those who had grateful and internal acceptance of wheelchair use did. The mean years of wheelchair use did increase as the categories of wheelchair acceptance progressed. It is possible that these are not static categories of acceptance, but progressive. It is possible that those that viewed the wheelchair as a part of themselves may actually have gone through a reluctant and then grateful acceptance category before they progressed to internal acceptance of wheelchair use. Conversely, it is possible that those who had reluctant acceptance of wheelchair use may actually progress to grateful acceptance and later internalized acceptance in later months or years. This would require further investigation, using a longitudinally designed study performed over many years.

Wheelchair use meant increased independence for some of the study participants. Those able to propel themselves with the wheelchair experienced increased independence in indoor and outdoor mobility. Independence was highly valued as the participants were dependent on their caregivers in so many areas of daily life. When a device was able to increase independence, it was greatly appreciated. It brought more of a sense of control over activities done and over one's life as a whole, allowing an increased sense of continuity with past independence categories. The more independence, or less dependence, that the wheelchair brought, the more appreciative the participant was of the wheelchair, e.g. those with internal acceptance spoke more about independence than dependence issues with the wheelchair.

The value of a mobility device in increasing independence, in other studies, led to increased acceptance and use of the device (Pippen & Fernie, 1997; Rush & Ouellet, 1997; Cott & Gignac, 1999). In Pippen and Fernie's study (1997), the walker was even viewed as

empowering symbol, a symbol of independence. For many of the participants in this present study, that would be true, but not for all as some did not have independent mobility with the wheelchair. However, it may be that as the wheelchair decreased the dependence on the caregiver, wheelchair use acceptance increased. The wheelchair increased mobility for all participants but did not increase independent mobility for all. Independence is highly valued in our society. It brings a sense of control, and autonomy. Maintenance of independence, at least to some degree, brought increased continuity between past and present.

The interrelated themes of independence and dependence among stroke survivors are also found in Secrest and Thomas (1999). In that study, participants reported struggling with the loss of their independence and abilities. This endangered their sense of themselves, decreasing control over their lives. Participants in this present study valued independence and tried to decrease dependence as much as possible. This could be in response to the desire for continuity in internal patterns of their lives. Further discussion regarding dependence is in the external patterns section, as it involves relationships.

Overall, the wheelchair was viewed as an aid. It was not seen as a visual reminder of loss as has been found in previous studies (Gitlin, Luborsky, & Schemm, 1998; Lupton & Seymour, 2000). Participants in this study used many assistive devices and had altered limb use that would also remind them of losses without even considering the wheelchair. With the length of time using wheelchair being two years and greater, it could be that participants had already dealt with issues of loss and now looked on these devices as aids to compensate for losses rather than as reminders of losses. The wheelchairs were viewed as tools that assisted with bodily function and contributed to the experience and presentation of themselves, as described by

Lupton and Seymour (2000) for other technologies but not for wheelchairs.

### External Patterns

The stroke brought many discontinuities to external patterns, such as living environment, social roles, activities, and relationships. Most, but not all, participants remained in the same home as prior to the stroke. Two participants moved to apartment/condominium living quarters, thus bringing discontinuity to external patterns in their lives. All participants used other assistive devices besides the wheelchair, which were brought into the home environment, bringing discontinuity to the home environment. Many others had renovations done to the home to accommodate for decreased mobility and wheelchair use which caused further discontinuity in external patterns. The wheelchair brought about discontinuity in external patterns, however, it also was a tool to bring some continuity to external patterns in the lives of the participants.

Participants found that the return home with the wheelchair brought many changes to the home environment and thus a more negative view of the wheelchair. It is possible that their sense of functional and physical loss was reinforced by the need to change their own familiar environment. Becker (1993) also found that there were changes to self-image at this time, as evidenced by negative descriptors such as 'cripple' used to describe themselves. It is possible that, in this study, the participants experienced this negative self-image when returning home, which, in turn, led to a more negative view of the wheelchair at this time. It should be emphasized that even though the view of the wheelchair was more negative, it still was mostly positive overall. Again, the need for the wheelchair was evidenced and its benefits experienced on a daily basis.

Wheelchair use meant increased mobility. Mobility was compromised for all

participants, some to a greater extent than others. Mobility was extremely important to the participants with some even expressing the thought that mobility is life. The wheelchair, in this present study, was highly valued for its role in increasing mobility within and/or outside the home. Previous research has found that the loss most often mentioned by stroke survivors was mobility (Mumma , 2000) . Mobility is crucial to life. Mobility is needed for self-care, other activities of daily living, most avocational pursuits, and community participation. The wheelchair was an enabler by allowing increased mobility and thus the opportunity to continue in vital and valued activities, providing continuity between past and present. Research has previously shown that mobility and other devices were accepted more readily as stroke survivors and others with disabilities thought about the alternate to not using the device - confinement and immobility (Gitlin, Luborsky, & Schemm, 1998; Lupton & Seymour, 2000). In this study also, the thought of the immobility that would result without the wheelchair led to its acceptance. Participants spoke about the immobility they would experience if they were without the wheelchair. As mobility categories with the wheelchair approached the ideal for the participant, the wheelchair was accepted more fully.

The wheelchair negatively and positively affected external patterns with respect to activities and social roles, and community participation. The wheelchair enabled many participants to continue going to places of worship and doctors offices that they had attended for many years. However, the wheelchair also caused discontinuities as some places were not wheelchair accessible or required too much effort to go to. Those places were no longer visited, resulting in discontinuity in external patterns. Some activities, such as going to the cottage or fishing, were impossible or complicated with a wheelchair. Thus, some social roles were altered

by wheelchair use while other roles were able to continue due to wheelchair use.

The need for the wheelchair seemed to help in initial acceptance of the wheelchair. The wheelchair was needed to continue social roles and various activities in the lives of the participants. This is consistent with the findings of Rush and Ouellet (1997) who found that genuine acceptance of assistive device use came with seeing the need for the mobility device, testing it, and seeing the benefits. Participants knew that mobility played a vital role in continuity of their lives. They actually found out the benefits of wheelchair use while in the rehabilitation hospitals. Many were actually glad for the wheelchair initially as it allowed them to get out of their hospital beds and explore more of the hospital. They spoke about the alternate to not using the wheelchair, which to them meant decreased mobility and obvious lifestyle consequences. This helped in terms of acceptance of the device. Gitlin, Luborsky, & Schemm (1998) also found that this understanding of the alternate of not using the device helped with acceptance. Interestingly, participants in this study who had to rely on the wheelchair for full-time mobility did not view the wheelchair any more positively than any of the other participants, as one might think when one considers that they would benefit even more from the device.

Freedom is mentioned in other studies as a benefit of mobility devices and a motivator for device acceptance (Lupton & Seymour, 2000). Freedom, expressed by the participants in this study, was connected to doing what they wanted, when they wanted to do it. The wheelchair brought freedom and a sense of control to the participants. Those with reluctant acceptance of wheelchair use spoke of feeling confined when using the wheelchair. They felt restricted in their activities. However, those with grateful acceptance more often voiced feelings of freedom with wheelchair use. This finding is consistent with other studies that found

mobility device acceptance was assisted by the fact that it decreased confinement (Gitlin, Luborsky, & Schemm, 1998). Even though the wheelchair did bring increased mobility to all participants, many still felt confined. This was due to environmental barriers and impairment in body function and structure related to wheelchair use. The wheelchair brought mobility but not mobility to go everywhere and do everything. The wheelchair did not bring total freedom in mobility.

This confinement was probably expressed due to loss of some valued activities for participants. The stroke itself resulted in loss of some roles and activities, however, other activities were lost specifically due to wheelchair use. This loss in roles and activities in stroke survivors is well documented in the literature (Jongbloed, 1994; Secrest & Thomas, 1999; Becker, 1993; Reid, Rudman, & Hebert, in press). Gitlin, Luborsky, and Schemm (1998) found that mobility devices provided a mechanism for continued roles and activities. However, as seen in this present study, the wheelchair, by nature of its size, mechanics, and restrictions, often led to increased activity and role loss that might not be seen with other mobility devices. Also, the hemiplegic pattern of wheelchair use is restricting in the effort required for propulsion. Many spoke at length about activities they were no longer able to do.

Participants with reluctant and grateful acceptance of wheelchair use were frustrated with the manual wheelchair in the amount of effort needed to independently propel the device. Indeed, it was actually so difficult for some that mobility could not be independent. Participants, for the most part, used the hemiplegic pattern of wheelchair propulsion which has been shown to be more difficult, slower, and require more effort than a two-handed pattern (Kirby, Ethans, Duggan, Saunders-Green, Lugar, & Harrison, 1999). If propulsion had been

easier, independent mobility would have been enhanced with positive effects probable in terms of autonomy, control, and community participation.

Dependence, has been found to disrupt the previous patterns of interdependence among stroke survivors and their spouses and has been looked on negatively (Jongbloed, 1994). It changed the relationship between husband and wife. The wheelchair was found to increase dependence on others as the participants relied on the caregivers to perform duties such as fold the wheelchair, put it in the car, push the wheelchair on occasion, and arrange disabled transit. Participants in this present study wanted to decrease, not increase, dependence on caregivers. The wheelchair, although it decreased dependence for some participants, in some aspects, also increased dependence, and in that way it was looked upon less positively. Those with reluctant acceptance, as a group, expressed the most difficulty and frustration with independent wheelchair mobility. This necessitated increased dependence on others. This may have been a factor in their category of acceptance of wheelchair use. Those that used powered mobility spoke of decreased dependence on others as a definite benefit of the device. The powered mobility device was valued for its part in decreasing the dependence on others. It was gratefully accepted.

As in previous studies, power mobility devices allowed users to pursue previously valued roles, enact new and old roles that brought meaning to their life, increased independence, decreased dependence on others, and widened their world (Buning & Schmeler, 1999; Miles-Tapping, 1996). The powered mobility users could enjoy more freedom and independence when using the power devices than when using their manual wheelchairs. These participants mentioned the need for both mobility devices, manual and power, to enjoy both indoor and

**outdoor activities as they desired. The use of just manual wheelchair or just the power device would have restricted their activities. The availability and use of both devices allowed independence, freedom, increased mobility, increased spontaneity, and more continuity in lifestyle activities and roles.**

**Power mobility devices were viewed very positively and accepted swiftly. Those who used them expressed grateful acceptance. The power devices were not seen as a necessity but more of a luxury. They were accepted gratefully immediately upon possession and use. This is in contrast to other study findings that found that power mobility device users regarded a switch from manual to power mobility as a progression of disability or deterioration that is fought against and avoided as long as possible (Miles-Tapping, 1997). This difference might be explained by the fact that stroke is a non-progressive event, with a one-time effect on mobility, whereas those in the aforementioned study suffered from progressive diseases. In fact, in the present study, the powered mobility devices were even sought out independently by the two participants in the study who used them, with minimal to no input from rehabilitation professionals. The expansion of spatial boundaries, decreased effort required in propulsion, and decreased reliance on others provided by these devices were anticipated even before use and were actually proven upon use. Acceptance of power mobility devices appeared to be immediate as these devices were sought out independent of rehabilitation personnel.**

**The wheelchair brought varied social response. Participants in all wheelchair use acceptance categories expressed similar thoughts in this area. Previous research has shown that stroke survivors have concerns regarding social acceptance of mobility devices even prior to discharge from hospital (Gitlin, Luborsky, & Schemm, 1998). Research has also shown that**

stroke survivors and other individuals with disabilities were concerned about stigma when using mobility devices (Rush & Ouellet, 1997; Pierce, 1998; Cott & Gignac, 1999). Interestingly, the word 'stigma' was only mentioned once by participants and that was by someone who said that there was no stigma to using a wheelchair. Most participants spoke of positive society response, especially from family and friends. As found in a study of walker users, participants spoke of society becoming more accepting of those with disability and the fact that there are many more users of mobility devices seen in public than there has been previously (Pippen & Fernie, 1997). This improvement in society response due to exposure, could be seen as a result of improved social policies and services, and improved device design and availability. Brooks (1991) also found more positive than negative society reaction to assistive device use. It is not clear whether this positive society response may have been a factor in the overall positive view of the wheelchair shown by all participants. Society response was a factor in community participation but to a lesser extent than other factors.

The one participant using a scooter did find that using the device detracted attention away from himself, as people commented on his scooter and not on him. This phenomenon has been found in other research (Lupton & Seymour, 2000), where the use of a wheelchair tended to detract attention from the identity and individuality of the person using it. With this phenomenon, the wheelchair is the focus of the conversation, with little attention being paid to the user. In this present study, only the one participant mentioned this reaction from others, and it did not seem to affect his participation in the community.

### Developmental Goals

Developmental goals, including personal goals, inner life, spiritual growth and evolution

of self, affected and were affected by wheelchair use. Personal goals had to be re-evaluated when the stroke and need for the wheelchair entered the life of the stroke survivor.

No questions were asked during the interviews specifically regarding this area therefore it was difficult to assess whether developmental goals changed in the participants. Two of the participants, one with reluctant acceptance of wheelchair use and one with grateful acceptance of wheelchair use, did speak about re-evaluating life after the stroke occurred. One spoke of examining his life to see where it was going and whether it was interesting and worthwhile. This participant did not elaborate further so it was difficult to determine if and how this internal examination had changed his developmental goals. However, this participant with reluctant acceptance of wheelchair use, had a personal goal to improve his ambulation so that he did not have to use a wheelchair anymore. Much of his time and energy was focused on stroke recovery, specifically ambulation. In contrast, another participant who showed grateful acceptance of wheelchair use seemed to be more content with his situation and spoke about the fact that he was endeavoring to be the same person he was prior to wheelchair use. It seemed that he continued to maintain his personal goals of being a man of integrity, being helpful and kind to others.

One participant with internal acceptance of wheelchair use seemed to have a personal goal of helping others deal with the onset and consequences of a stroke. He was a volunteer with a stroke group and an executive member of a community support organization dealing with strokes. It is unknown whether this type of service to others was continuous with his previous lifestyle. This same participant was the one who spoke about 'growing into' wheelchair use.

Spiritual growth goals among the participants were apparent as many kept up contact

with places of worship and other religious affiliations even when wheelchair use made continuity in this area somewhat problematic. Some churches were inaccessible and much effort and planning was required in attending services, even in 'accessible' places of worship. However, when participants were not able to attend services, they were pleased to report that pastors visited them, sermon notes were sent to them, and they were able to attend Bible studies.

Family relationships were extremely important to all participants. Although inter-dependency patterns among family members had changed, the importance of the family relationships had not. The developmental goal of continuing the evolution of ongoing family relationships was maintained. If the homes of children were not wheelchair accessible, the children came to visit the participants in their home. Long distance travel was engaged in to keep up contact with family and friends in overseas homelands. The wheelchair did assist in the long distance travel.

#### Adaptive capacity

The advent of the stroke and need for the wheelchair brought about many changes, necessitating coping and adapting on the part of the stroke survivor. The stroke event changed the physical, mental, and emotional capacities of the participant. The need for and use of the wheelchair changed the home environment, activities, self identity, among other aspects of the stroke survivor's life. Adaptation for the participants meant that they had to mobilize coping skills and resources in order to deal with these changes. According to continuity theory, adults are motivated to continue to use the external and internal patterns they have spent so much time and energy developing (Atchley, 1999). Coping resources that were mentioned by the

participants were: family support and encouragement, a positive attitude, religiousness, perseverance, attending community support groups, and being as active as possible. These resources and strategies allowed some sense of continuity of life and helped the participants adapt to the consequences of stroke and the need for the wheelchair.

The coping resources of religiousness, community support groups, and positive attitude showed trends of increasing proportionally in the categories of wheelchair use acceptance. These trends, although interesting to note and consider, do not meet saturation and need to be explored in more depth in further studies in order to draw any conclusions about their effect on wheelchair use acceptance with this stroke population.

Participants spoke of other changes in their lives, aside from the stroke, that required adaptation in the past and present. They spoke of retirement, death of friends, change in living environment, change in health of the spouse, and varied other health difficulties of their own. Some participants spoke of using similar strategies of adaptation to the need for the wheelchair as they had used for adaptation to these other changes in life that they had encountered. Changes seemed to be an accepted part of life. Adaptation to stroke and wheelchair use was a drastic change but was not the only change being dealt with in the lives of the participants.

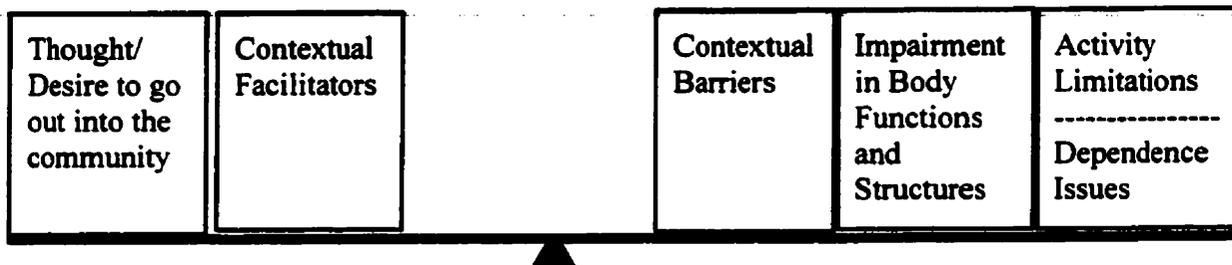
Adaptation to wheelchair use can be discussed specifically with regard to activity categories. Prior to this discussion, a model of community participation will be presented to clarify the positive and negative impact of the wheelchair on the activity category of the participants outside the home. The varied activity categories of the participants will then be discussed.

#### Model of Factors Affecting Community Participation

**Wheelchair use was an enabler for community participation, however, participants often found community activities problematic due to various barriers, and so would chose to stay home rather than go out. This increased their social isolation. Social isolation among stroke survivors has been noted in several studies (Astrom, Asplund, & Astrom, 1992; Becker, 1993; Burton, 2000; DeSepulveda & Chang, 1994; Pound, Gompertz, & Ebrahim, 1998).**

**Participants could identify barriers and facilitators to wheelchair use in the community. A few voiced frustration concerning wheelchair access issues, as other studies have found (Pierce, 1998). Many felt, though, that opportunities were improving for wheelchair users, as more facilitators, such as disabled transit and automatic door openers were more widely available in the last few years.**

**To incorporate and further clarify the impact of the factors affecting community participation a model has been developed. Figure two depicts a scale with the fulcrum in the middle. On the left side of the fulcrum is the thought, desire, or request to go out into the community as well as contextual facilitators, both personal and environmental. This is weighed against the factors on the right side of the fulcrum, the contextual barriers (personal and environmental), impairments in body function and structures, and activity limitations including dependence factors. In order for the elderly stroke survivor who is using a wheelchair to go out into the community, this desire to participate in the community must be weighed against these three factors. In considering community participation, the participants in this study often found that the environmental, personal, and dependence factors weighed too heavily and it was easier to stay at home than venture out. If they knew the destination had facilitators rather than barriers that increased the likelihood of engaging in a community activity.**



**Figure 2.** Factors Affecting Community Participation

Contextual facilitators, both environmental and personal are included on the left side of the fulcrum with the thought or desire to venture out into the community. Knowing that a destination was wheelchair accessible (environmental facilitator) and anticipating the positive well-being felt on engagement in the activity (personal facilitator) was weighed against the contextual barriers, impairment in body functions and structures, and activity limitations with dependence on others. If the scale tipped to the left, in other words the pros outweighed the cons, then the participant would engage in the community activity. If, however, the sidewalks were very uneven, the weather bad, the outing too much of a challenge to physical endurance, and the caregiver was not up to the event, the right side of the scale would outweigh the left and the participant would choose not to engage in the community activity. Sometimes the caregiver would weigh these factors and make the decision for or with the participant.

The thought or desire to go out into the community came from the participant him/herself, the caregiver, or some significant other. Personal facilitators, such as a feeling of well-being or continuance of some social role, helped to decide in favor of community participation. Environmental facilitators also contributed positively toward community

participation as the participant was more likely to go, or sometimes, only able to go, to places that accommodated the wheelchair.

Contextual barriers weighed against community participation but because participants had discovered long before which destinations were wheelchair accessible and which ones were not, these barriers did not seem to carry as much weight in the decision to participate in a community activity as other factors. Participants had already adjusted their lifestyle, limiting their participation and destinations to those that did not have as many environmental and personal barriers. It is possible that earlier on in the career of the participant as a wheelchair user, these contextual barriers might have weighed more heavily in the balance. Some participants did have the option to navigate stairs with a cane or walk in through a narrow doorway, thus negating some environmental barriers for the wheelchair. The effort necessary for manual wheelchair propulsion was a contextual barrier also, making the wheelchair user more dependent on the caregiver.

Impairment in body function and structure, such as altered body functions, perceptual deficits, and decreased sitting tolerance came into play when making a decision about whether to go outside the home or not. If the anticipated trip was going to take a long time, or if it required much effort on the part of the participant, then it would weigh heavily against going out into the community.

Dependence issues, due to activity limitations, seemed to weigh the heaviest against community participation. Participants were very conscious of caregiving burden and going out into the community often increased burden on the caregiver as it required preparation, planning, lifting of wheelchair, driving or arranging disabled transit, etcetera. Few participants ventured

out into the community without caregiver accompaniment.

If some of the factors to the right of the fulcrum were lessened or eliminated then participants were more likely to engage in community participation. Power mobility devices seemed to alleviate or negate some of the factors weighing against community participation. It seemed to mostly affect the areas of personal and dependence factors, but still had an effect also on eliminating some contextual barriers. Community participation increased on acquisition of a powered mobility device for the two participants who used them.

In outlining and understanding the interplay of factors affecting community participation among the stroke survivor participants in this study, it is understandable that activity categories of these individuals will be affected by the stroke and the need for a wheelchair. Further discussion of activity categories follows.

#### Activity Levels

Continuity theory contends that people who cannot avoid role loss or constraints on role behaviour will try to preserve the pattern of activity but will cope with functional limitations by reducing the overall level of participation. Of the six response, or activity level adaptations, that Atchley (1999) outlines, three were seen in this study. As mentioned, activity levels prior to the stroke could only be determined by the participant's recollection, due to the study's design. However, participants did speak clearly of their present activity level and spoke generally about their activities prior to the stroke and need for the wheelchair. The wheelchair affected activity levels, specifically community participation both positively and negatively.

The internal acceptance category showed the most continuity with both participants showing decline in activity level but continuing, for the most part, with engagement in similar

activities as prior to wheelchair use. The least continuity among participants is seen in reluctant acceptance category of wheelchair use. The grateful acceptance category was between the other two categories in terms of continuity of activity. Therefore, it is possible that acceptance of wheelchair use was linked to the continuity or discontinuity of activity patterns of the participants. Meanings such as increased mobility, independence and dependence, stem mostly from the wheelchair's ability to assist in continuity in activity levels, preserving the activity pattern. Acceptance category would reflect these meanings.

Power mobility use allowed the most continuity in activity levels. The powered mobility device allowed the participants who used them to pursue interests and lifestyles to which they had previously been accustomed. For the one participant, having powered mobility meant that he could continue with his distribution of religious literature and do the grocery shopping, and for the other participant the powered mobility meant that he could pick up a paper, visit the donut shop, and tour around town as he was accustomed to doing prior to his stroke. So in addition to powered mobility devices increasing community participation, they also appear to allow more continuity in activity levels. The fact that the powered mobility device users did not show evidence of internalized acceptance may be partially due to the relative newness of these devices (less than two years), and the fact that it was only used for outdoor mobility. It was a luxury, not a necessity.

It would be difficult to say, as continuity theory would state, that there was no negative effect on well-being with moderate activity decline. Due to the nature of the effects of the stroke, with its impairment in body function and structure and activity limitations and resulting discontinuity, no change in well-being is highly unlikely in this population. Stroke can affect

**emotional centres in the brain, causing emotional lability, so it is somewhat problematic attributing well-being to activity category only. In this sample of stroke survivors there appeared to be at least mild negative impact on well-being in all participants.**

## **Chapter Eight: Conclusion**

Continuity of life appears to play a key role in the understanding of the views of wheelchairs, acceptance categories and meanings of wheelchair use, and community participation among the elderly stroke survivors in this study. Stroke survivors in this study were faced with many discontinuities in the internal and external patterns of their lives. Developmental goals were altered to some extent. The wheelchair, although it brought discontinuities to the lives of the participants in this study, was seen as a tool for continuity. As the wheelchair provided opportunity for increased continuity in the lives of these stroke survivors, it was accepted and appreciated more fully and viewed more positively. The wheelchair allowed a link to past lives, allowing the stroke survivors to continue with some of the activities that brought meaning to their lives, thus affecting self-concept and well-being.

Powered mobility devices, used by two participants appeared to allow further continuity in activity levels and social roles and were valued highly by the participants that used them. These devices were used in conjunction with the manual wheelchair to allow optimum independence and activity and ultimately, continuity with the pre-stroke life.

Wheelchair use meant continuity and discontinuity with the past. It affected internal and external patterns, developmental goals, and activity levels and required adaptive capacity. The meaning the wheelchair had for the individual led to the view of the device and the acceptance of wheelchair use.

In summary, this study found that:

- Wheelchair use was accepted on different categories among this population of elderly stroke survivors. The categories of acceptance were; reluctant acceptance, grateful

**acceptance, and internal acceptance.**

- **Wheelchair use had a variety of meanings among these stroke survivors. Increased mobility, varied social response, and loss of some valued roles were common to all three wheelchair use acceptance categories. Aspects of independence, freedom, and spontaneity varied in degree among the three acceptance categories.**
- **Community participation was positively and negatively affected by wheelchair use. Barriers and facilitators affecting wheelchair use in community participation included impairments in body function and structure, activity limitation, and contextual factors. Dependence factors weighed heavily in participants' level of community activity.**
- **There was discontinuity evident in the lives of the stroke survivors in this study. Wheelchair use and acceptance appeared to be influenced by, and had an influence on continuity of life with regards to internal and external patterns, and developmental goals of the stroke survivors in this study, requiring adaptive capacity. Activity levels declined with the advent of the stroke and the need for a wheelchair, with those with internal acceptance of wheelchair use showing the most continuity in activity level and type. As the wheelchair provided opportunity for increased continuity in the lives of these stroke survivors, it was accepted and appreciated more fully and viewed more positively.**
- **Powered mobility devices, used by two participants in the study, were viewed very positively and aided in providing independence, freedom, and continuity of life for the users.**

## **Chapter Nine: Limitations of Study and Implications**

### **Limitations of Study and Future Directions For Research**

Due to the nature of this qualitative study and the in-depth interviews required, the number of participants was not large. Participants were all recruited from the Metro Toronto area. Men and women were not equally represented, with only two of the ten participants being female. The ability of the participants to verbalize their feelings and experiences was of paramount importance in this qualitative study. This meant that those with aphasia or any type of communication difficulties could not be included as subjects in this study. In spite of these limitations, themes and concepts were generated that would allow for further exploration in later research, to explore the transferability of the findings to a range of settings.

Some of the concepts explored, such as adaptation to wheelchair use and continuity/discontinuity of activity level could be explored in more depth by use of a longitudinal study with an accurate index of activity levels past and present. Also, a longitudinal study, exploring acceptance categories of wheelchair use among stroke survivors, could help to discover whether these categories are progressive or static. Appendix H shows that the mean length of time using a wheelchair increases as wheelchair acceptance categories become more positive. However, the length of time that individual participants had been using a wheelchair was not associated with the category of acceptance. Further research would help to determine whether length of time using a wheelchair is associated in any way with acceptance of the device.

Coping resources, as they relate to acceptance of wheelchair use could also be a topic for further investigation, in order to provide greater understanding of the acceptance process in

relation to coping resources available to the stroke survivor.

The benefits of powered mobility devices needs to be explored in more depth. Only two of the ten participants in this study owned and used powered mobility devices. Research is needed to explore more fully the benefits and drawbacks of these devices in this population, exploring issues such as continuity/discontinuity and quality of life.

### Implications

The results of this qualitative inquiry have implications for rehabilitation personnel, wheelchair manufacturers, and society. These will be discussed below.

#### Implications for rehabilitation personnel

First and foremost, therapists who prescribe wheelchairs need to take time to investigate life continuity issues with stroke survivors before prescribing mobility devices. The pre-stroke value of mobility and category of activity are two areas that need special attention from the prescribing therapist. It may be necessary to re-allocate available time with the stroke survivor, understanding that from the stroke survivor's perspective time might be better spent looking at issues of community participation and continuity of life, rather than practicing such things as toilet transfers.

The need and desire for powered mobility devices should be fully discussed with the stroke survivor, especially with regards to continuity of life. The stroke survivor should be made aware of add-on power packs for manual wheelchairs, types of power wheelchairs, and types of scooters. Trials of these devices might be beneficial to allow full understanding of maneuvering and benefits. Trials should take place in the rehabilitation hospital environment

**but also in the stroke survivor's home environment and community.**

**The ease or effort of mobility with the device needs to be assessed inside and outside the home environment. If the wheelchair mobility requires too much effort this will likely result in frustration and decreased community participation for the stroke survivor as well as increased dependence on the caregiver for mobility. Time should be taken training the stroke survivor for mobility, especially if s/he is using the hemiplegic pattern for wheelchair propulsion.**

**Wheelchair propulsion over inclines, narrow passageways, and other environmental challenges needs to be practiced. It might be necessary for the stroke survivor to undergo strengthening of the non-hemiplegic arm and leg to increase ease and endurance of wheelchair propulsion is using the hemiplegic pattern. Discussion should take place regarding challenges to wheelchair propulsion in all weather conditions. This is especially important with our Canadian winters.**

**The caregiver's health status and ability and willingness to assist with wheelchair mobility and lifting wheelchair into car, etcetera also needs to be fully explored. With manual wheelchair use, much is physically required of the caregiver. The caregiver should be educated about this.**

**Proper prescription for seating is essential. Stroke survivors, especially those that use the wheelchair for full-time mobility need very comfortable seating to have maximum sitting tolerance. Estimated time-frame for seating replacement should also be reviewed with the stroke survivor, including funding availability for replacement.**

**Those prescribing wheelchairs should follow-up with the stroke survivor to ensure proper and optimum use and to help solve any problems encountered as seasons change and new environments and activities are encountered.**

### **Implications for wheelchair manufacturers**

The hemiplegic pattern of manual wheelchair propulsion requires a lot of effort on the part of the stroke survivor, and increases dependency on caregivers. New design considerations for manual wheelchairs for those using the hemiplegic pattern of wheelchair propulsion need to be explored. Presently, those using this hemiplegic pattern are using the same type of manual wheelchair that was designed for two-handed use.

Powered mobility devices that are scaled to the needs of stroke survivors are needed. Powered mobility devices offered tremendous benefit to the participants in the study who used them, however most participants that did not have them did not feel that they would be able to handle them, for one reason or another. More variety of powered mobility devices that offer increased ease in outdoor mobility based on a variety of skill category and yet could also be easily used inside the home as required would be very beneficial to stroke survivors. Ease in getting these devices in and out of the car is also a necessary consideration.

Ensuring proper safety of powered mobility devices and educating stroke survivors of the reliability of the devices would increase acceptance and use among this population of users. Those in the study who did not use powered mobility devices feared them mostly due to possible mechanical failure.

Creative solutions for financing powered mobility devices, such as leasing options, need to be available for stroke survivors. Most stroke survivors in this study were on a limited income with financial resources stretched for other assistive devices, home renovations, and other daily living requirements. The expense of a powered mobility device would not be easily accommodated in their budget.

### **Implications for society**

There are several implications for society that result from this study. Society response to those with wheelchairs appears to be improving, however, there is still room for further improvement. People in society need to slow down around, and have increased patience with elderly stroke survivors who use wheelchairs. People in the community should consider the person in the wheelchair, remembering that they have an identity other than a wheelchair user. Comments regarding the mobility device should be kept to a minimum and only be made after one has greeted the user as an individual first.

In order to maximize community participation for elderly stroke survivors, society needs to continue to improve environmental facilitators such as disabled transit services and automatic door openers, and alleviate more environmental barriers such as bumpy sidewalks and lack of wheelchair accessible caregiver-friendly washrooms. Clear guidelines should be in place regarding wheelchair accessibility.

Finally, funding should be available for powered mobility devices for those who have been assessed by a qualified professional. Presently, in Ontario, the provincial Assistive Devices Programme of the Ministry of Health, will only provide funding for what is deemed to be basic and essential for the client. For example, if a stroke survivor is able to use a manual wheelchair in their living environment, but would have improved quality and continuity of life using a powered mobility device, the programme will only fund for the manual wheelchair. Quality and continuity of life must be given increased consideration when funding mobility devices.

**Appendix A**  
**Participant Demographics**

Participant	Gender	Age	Time since CVA	Main Caregiver	Living Accommod.	Education Category	Income Category (in dollars)	Type of Wheelchair
1	M	78	4 yrs	Spouse	Apartment	Gr. 1-8	10,000 to 19,999	Manual and Scooter
2	M	75	6	Spouse	House	High School	40,000 to 49,999	Manual
3	M	77	16	Spouse	House	High School	30,000 to 39,999	Manual
4	F	73	5	Spouse / Homemaker	House	High School	10,000 to 19,999	Manual
5	M	74	2	Spouse	House	College / Univ.	Refused to answer	Manual
6	M	72	2	Spouse	House	Gr. 1-8	20,000 to 29,999	Manual
7	M	80	10	Spouse	Condo	College / Univ.	Refused to answer	Manual
8	M	70	4	Spouse	Apartment	High School	10,000 to 19,999	Manual
9	F	79	3	Spouse	House	High School	40,000 to 49,999	Manual
10	M	77	4	Spouse	House	College / Univ.	50,000 or more	Manual and Power

**CONSENT FORM - STROKE SURVIVOR**

**Title of Study: "Factors Influencing the Occupational Performance of Elderly Stroke Survivors Who Use Prescribed Wheeled Mobility Systems in the Home Environment: Users' and Caregivers' Perceptions"**

**Principal Investigator:** Denise Reid, Ph.D. (416) 978-5937

**Co-Investigators:** Deborah Rudman, M.Sc. O.T. (416) 978-8541  
Debbie Hebert, M.Sc. (416) 597-4494 ext. 3505

**Research Assistant:** Donna Barker, B.Sc. O.T. (416)226-6790 ext.7208

I have been invited to participate in the study described in the attached information sheet. I have read and understood the information sheet related to this study. The details of the study were explained to me by Donna Barker.

I will be free to ask questions about this study at any time. I understand that the first interview session will be tape recorded and that confidentiality of information derived from the study about me will be preserved.

I understand that the researchers may decide in the future to conduct a secondary study using data from this study, and possibly re-interviewing some of the study participants. The principal investigator and possibly other researchers who are not members of the present research team may be involved. This secondary study will not proceed unless it receives ethical approval from the University of Toronto and other

**participating institutions. The same confidentiality and privacy restrictions will apply to this study. At the completion of the research all taped interviews will be deleted.**

**I realize that I can withdraw from the study at any time without any consequences to the care that I currently receive.**

**Participant Name in Block Letters**

**Participant Signature**

**Witness Name in Block Letters**

**Witness Signature**

**Date**

**I have been fully informed of the study's nature and expectations, and I agree to participate in the above-named study.**



**University of Toronto** Approval Letter

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**OFFICE OF RESEARCH SERVICES**

**PROTOCOL REFERENCE #4937**

**January 11, 2000**

**Professor Denise Reid  
Department of Occupational Therapy  
256 McCaul Street  
University of Toronto**

**Dear Professor Reid:**

**Re: Protocol entitled "Factors Influencing the Occupational Performance of Elderly Stroke Survivors who use Prescribed Wheeled Mobility Systems in the Home Environment: Users' and Caregivers' Perceptions" by Professor D. Reid**

---

**We are writing to advise you that a Review Committee composed of Professors B. Kirsh and R. Renwick has granted approval to the amendment to the above-named research study as per your letter of Dec. 9, 1999 with the interview guide.**

**During the course of the research, any significant deviations from the approved protocol (that is, any deviation which would lead to an increase in risk or a decrease in benefit to human subjects) and/or any unanticipated developments within the research should be brought to the attention of the Office of Research Services.**

**Best wishes for the successful completion of your project.**

**Yours sincerely,**

A handwritten signature in black ink, appearing to read "Susan Pilon".

**Susan Pilon  
Ethics Review Officer**

**SP/mr Enclosures  
Cc: Prof. J. Friedland, Chair**

## Appendix D

### Interview Guide

**Interviewer Introduction:** “The purpose of this study is to understand more fully the experiences of stroke survivors who use a wheelchair in their home and community. I specifically want to hear from you concerning issues such as how you adapted to wheelchair use, whether there have been changes to your self-identity since having a stroke and using a wheelchair, and what your category of community participation is. If you do not wish to answer any question during the interview, you are free not to do so. I appreciate your willingness to partner with me in this project by spending this time with me. If you have any questions for me at any time, please feel free to ask”.

- **Please tell me about when you first received your wheelchair.**  
Probe: when, how, who helped with fitting, training
- **a) Has your life changed since you started using a wheelchair?**  
Probe: In what ways?  
**b) What is your life like with the wheelchair?**  
Probe: positives and negatives
- **Can you tell me if using a wheelchair makes your life harder?**  
Probe: inside/outside your home, specific examples
- **Can you tell me if using a wheelchair makes your life easier?**  
Probe: inside/outside your home, specific examples
- **Can you tell me if using a wheelchair has made you feel differently about yourself?**  
Probe: how, why
- **If you didn't have this wheelchair, can you tell me if and how things be different for you?**  
Probe: inside your home, outside your home
- **What advice would you give to someone who is just beginning to use a wheelchair?**  
Probe: any necessary adjustments

Appendix E  
Data Sheet

**DATA SHEET**

**Participant ID #** \_\_\_\_\_ **Date** \_\_\_\_\_

**MEDICATIONS**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**TRANSPORTATION**

Does respondent drive a car? \_\_\_\_\_ Does respondent have a valid driver's license? \_\_\_\_\_  
Does caregiver drive a car? \_\_\_\_\_ Is there a family member or friend that is able to  
drive respondent where s/he needs to go? \_\_\_\_\_

**TRANSFERS/ACCESS**

How many people need to assist respondent with transfer into/out of car? \_\_\_\_\_  
How many people need to assist respondent with access into/out of house? \_\_\_\_\_  
How many people need to assist respondent with transfer into/out of bed? \_\_\_\_\_

**WHEELCHAIR DESCRIPTION**

(Photograph Taken \_\_\_\_\_)

Height \_\_\_\_\_ width \_\_\_\_\_  
Armrest type \_\_\_\_\_ footrest/leg rest type \_\_\_\_\_  
Seatbelt \_\_\_\_\_ extended brakes \_\_\_\_\_  
Anti-tippers \_\_\_\_\_ upholstery colour \_\_\_\_\_  
Quick-release axles \_\_\_\_\_ grade-aids \_\_\_\_\_  
Wheel/Caster type and size (eg. pneumatic/solid, mag/spoke) \_\_\_\_\_

Arm Support (eg. Trough, lap tray) \_\_\_\_\_  
Cushion Type \_\_\_\_\_ Cushion Condition \_\_\_\_\_  
Back Type \_\_\_\_\_  
Other \_\_\_\_\_

Fit of Wheelchair to Person (interviewer's judgment)

\_\_\_\_\_  
\_\_\_\_\_

Fit of Wheelchair to Environment (interviewer's judgment)

\_\_\_\_\_  
\_\_\_\_\_



Grab Bar		
Bathbench/Bathchair		
Versa frame		
Long-handled Shower Hose		
Bath brush		
Bath Mit		
Non-slip Mat		
Other		

**Personal Care - Feeding**

Device	Owned	Used Regularly (indicate how often)
Adapted Cutlery		
Plate guard		
Cut-out cup		
Rocker Knife		
Other		

**Functional Mobility**

Device	Owned	Used Regularly (indicate how often)
Wheelchair		
Walker (indicate type)		
Cane (indicate type)		
Scooter		
Other (indicate type)		

Device	Owned	Used Regularly (indicate how often)
Sliding Board		

Saska Pole		
Hospital Bed		
Ramp		
Elevator		
Other		

**\*PRODUCTIVITY\***

**Household Management**

<b>Device</b>	<b>Owned</b>	<b>Used Regularly (indicate how often)</b>
Adapted Cutting Board		
Sandwich Spreader		
Kettle Tipper		
Adapted Can/Jar Opener		
Dycem		
Other		

**\*LEISURE\***

<b>Device</b>	<b>Owned</b>	<b>Used Regularly (indicate how often)</b>
Book Holder		
Card Holder		
Clamp-on Device		
Magnifying Glass		
Telephone Adaptation		
Other		

**Appendix F**  
**Field Note Form**

**Participant ID #** \_\_\_\_\_ **Date** \_\_\_\_\_

**Physical Appearance of Participant**

**Paralysis Evident:** Face \_\_\_\_\_  
                          U/E \_\_\_\_\_  
                          L/E \_\_\_\_\_  
                          Trunk \_\_\_\_\_

**Hair:** \_\_\_\_\_  
**Clothes:** \_\_\_\_\_  
**Odour Present?** \_\_\_\_\_

**Affect of Participant During Interview**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Disruptions During Interview**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Appearance of Home**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Significant Comments Made By Participant Not Recorded On Tape**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Other**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Appendix G

CODES with their ABBREVIATIONS, and DEFINITIONS

CODE	ABBREVIATION	DEFINITION
Adaptation/ Adjustment	A/A	- any mention of the physical or emotional process of change (undergone by the stroke survivor (SS) or his/her significant others) involving adaptation and adjustment since having the stroke and/or acquiring the wheelchair (e.g. changing furniture around in the house, adjusting to the functional loss of a limb)
ADL - self-care	ADL	- any mention of dressing, bathing, toileting, or grooming done by the SS (including need for assistance from others)
Attitude/Outlook	A/O	- any mention of how the SS views his/her present situation, his/her surroundings, his/her past or future; the present attitude or emotional outlook of the SS, whether it be positive or negative
Community Activity	CA	- any mention of any present or past community involvement of the SS since the CVA, whether it be formal or informal. This can include group involvement, shopping trips, religious activities, or just going out for a walk
Concerns/Worries	C/W	- any expressed concerns, worries, or fears that the SS has presently or since the stroke
Dependence on Others	DO	- any mention of physical care or help given to the SS by other people (regardless of whether or not it be by the primary caregiver) or of any emotional reliance on other people
Financial	FIN	- any mention of finances, be it statements of fact about income, costs, or expenditures, or any other concerns about financial matters
Long Distance Travel	LDT	- any mention of trips (out of immediate city) taken or thought about since having had a stroke

<b>Loss</b>	<b>L</b>	- any mention of physical, material, or emotional losses experienced by the SS or his/her family or friends since having had a stroke. This could also include loss of roles
<b>Mobility in the Community</b>	<b>MIC</b>	- any mention of the SS going outside of his/her home, within the same city, whether it be with the use of a personal mobility device or by car or foot
<b>Mobility in the Home</b>	<b>MIH</b>	- any mention of how the SS gets around in their own home, regardless of mobility devices used or not used
<b>Other Mobility Device (without use of wheelchair)</b>	<b>OMD</b>	- any mention of mobility, since the CVA, that occurs inside or outside the home without the use of manual or power wheelchair (or scooter). Eg. The SS may mention that s/he uses a cane in the house or holds onto furniture or someone's arm for support
<b>Personal Control</b>	<b>PC</b>	- any mention by the stroke survivor of any feelings of control over events, happenings, his/her body or his/her surroundings (or lack thereof)
<b>Self</b>	<b>SELF</b>	- any mention of how the SS feels about him/herself, how they view themselves or would describe themselves
<b>Physical Limitations</b>	<b>PhL</b>	- any mention of present physical limitations experienced by the SS as a result of the stroke or other physical problems
<b>Power Mobility</b>	<b>PM</b>	- any mention of the use of power mobility (power wheelchair or scooter) - its advantages or disadvantages, whether the SS has ever considered using power, what s/he does use power for, etc.
<b>Practical Issues of Wheelchair Use</b>	<b>PI</b>	- any mention of practical issues of manual wheelchair use, e.g. maintenance, conveniences, inconveniences, physical barriers, features of the wheelchair

<b>Pre-Morbid Lifestyle/Activity Category</b>	<b>PML/A</b>	- any mention of the SS (or family's) activity category or lifestyle prior to the onset of the stroke, including self-care, productivity, or leisure
<b>Gain</b>	<b>G</b>	- any mention of physical, material, or emotional gains experienced by the SS or his/her family or friends as a result of the stroke or using the wheelchair. This could include new roles begun
<b>Psychosocial Support</b>	<b>PS</b>	- any mention of emotional reliance of the SS on other people, whether they be the main caregiver, family, friends, or acquaintances
<b>Roles</b>	<b>R</b>	- any mention of previous or present roles filled by the stroke survivor, e.g. spouse, parent, friend, leader, etc.
<b>Society Response</b>	<b>SR</b>	- any mention of how the general public or family or friends have responded to or do respond to the SS or to other people with disabilities (responses may be physical or verbal). This may also include the SS emotional comfort category in the community
<b>Stroke Event</b>	<b>SE</b>	- any mention of the events surrounding the actual time when the stroke occurred
<b>View of Wheelchair</b>	<b>VW</b>	- any mention of the how the respondent views the wheelchair, their thoughts about the w/c, whether they consider the w/c helpful or not, etc.

## Appendix H

### Category of Acceptance of Wheelchair Use and Length of Time Using Wheelchair

<b>Category of Acceptance/View of Wheelchair</b>	<b>Length of Time Using Wheelchair (in years)</b>
Reluctant Acceptance/ Wheelchair is a Necessity	2 , 4, 4, 6 (Mean = 4.0)
Grateful Acceptance/Wheelchair is a Great Asset	2, 3, 4, 10 (Mean = 4.75)
Internalized Acceptance/Wheelchair is a Part of Me	5, 16 (Mean = 10.5)

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