University of Alberta

Community Living after Stroke: An Ecological Model

by

Sharon Anderson

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Examining Committee

Dr. Kyle Whitfield, Faculty of Extension, School of Public Health

Dr. Laurel Strain, Department of Sociology, Director of the Alberta Centre on Aging

Dr. Alex Clark, Faculty of Nursing

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Abstract

Background: Over 80% of people who experience stroke survive, but for half, their level of activity drops significantly. Even survivors with mild disability become disengaged.

Research Question: Based on an ecological model, what perceived facilitators and barriers do stroke survivors encounter in their choice of everyday activities 1 to 6 years after stroke?

Methods: Situational analysis grounded theory.

Results: Disability changed participant's social position regarding their ability to control their own situation to dependence on other people to facilitate choice. Re-negotiating identity and position in society was an iterative process of scaffolding small tasks into activities through bargaining for access to practical support and inclusion into social situations.

Conclusions: Stroke survivors who experienced inclusion in their communities resumed some level of meaningful activities more successfully. However, some with mild disability had difficulty resuming activities as they were expected to system navigate and adapt on their own.

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CHAPTER 1

INTRODUCTION

The focus of this thesis is to explore how nine people who had a stroke 1 to 6 years ago have either resumed or have had difficulty resuming activities when they returned home. The researcher posed questions to participants about their experience of resuming activities in a single semi-structured interview either in their own home or in a community location of their choice.

The researcher’s aim in undertaking this project was to increase the limited understanding of how stroke survivors’ social and environmental contexts interact with biological impairments from stroke to enable or limit their choice of everyday activities. At the October 2007 Canadian Stroke Network (CSN) meeting, Dr. Nancy Mayo noted that there was no agreed upon definition for community reintegration. However, the client-centered definition of Mary Ann McColl and her colleagues (1998) defined community integration as “having something to do, somewhere to live, and someone to love” (p. 15). Dr. Mayo proceeded to suggest that the WHO ICF (2001) concept of “participation” defined as “involvement in life situation” or as “the lived experiences of people in the actual context in which they live” (pp. 14-15) should be the preferred terminology and measure of outcome after stroke.

Dr. Mayo stressed that “from the perspective of the health care system, many of the components of quality of life, such as jobs, housing, schooling and neighborhood are not attributes of health, thus are outside the purview of the health care system” (Canadian Stroke Network, 2008, p. 4). Although many healthcare professionals understand the social determinants of health, how to incorporate these into traditional healthcare systems and funding models focused on short-term illness needs is less understood. Therefore, a need exists to understand how the social determinants of health affect participation and what consideration of these might mean to stroke survivors and their families.

This study uses situational analysis grounded theory (Clarke, 2005) and a health promotion ecological model (Bronfenbrenner, 2005) to understand

and interpret the barriers and facilitators stroke facing survivors' everyday engagement in activities. Similarities and differences between the activities participants resume and did not resume were also compared.

1.0 Significance of Study

Canada has an enviable record of improved stroke prevention and treatment (Canadian Institutes of Health Information [CIHI], 2007; Field, Green, Roy, Pedersen, & Hill, 2004; Mayo, Nadeau, Daskalopoulou, & Cote, 2007). Stroke incidence rates have been decreasing since 1950. At the same time, the average survival time post-stroke has increased to 7 years (Heart and Stroke Foundation of Ontario [HSFO], 2007). Notably, after their symptoms are controlled, younger survivors have exactly the same chance of survival as anyone of their age and sex (CIHI, 2007; HSFO, 2007). The success of acute medical services to increase length of stroke survivors' lives is indisputable. However, ensuring that these added years are of good quality is now a challenge that researchers, clinicians, and policy-makers must address. Stroke survivors' quality of life is significantly lower than their age-matched peers (Clarke & Black, 2005). This has been related to lack of engagement in meaningful activity (Clarke & Black, 2005; Mayo, Wood-Dauphinee, Côté, Durcan, & Carlton, 2002).

Stroke compromises individuals' ability to participate in the daily activities they enjoyed pre-stroke. Indeed, after stroke, "inability to occupy one's time in a manner appropriate to one's age, sex, and background is by far the most problematic of all areas assessed" (Harwood, Gompertz, & Ebrahim, 1994, p. 825). Being able to resume valued pre-stroke activities is associated with superior self-rated quality of life. Conversely, being unable to do so is associated with reduced life satisfaction (Clarke & Black, 2005). Daily activities reflect the individual's internal needs, goals, motivations, preferences, and skills; however, activity levels are also affected by external constraints and opportunities (Horgas, Wilms, & Baltes, 1998; Law, 2002).

The definition of "community reintegration" incorporates activities. It is defined as "a process by which individuals with stroke are enabled to increase their participation in personal, family and social roles and thereby improve their quality of life" (CSN, 2008, p. 6). Community reintegration is a priority for Canadian stroke research (Bayley et al., 2007; Bhogal, Teasell, Foley, & Speechley, 2003). Therefore, it is surprising that despite the knowledge that stroke survivors are restricted in meaningful participation few evaluations have been performed into how stroke survivors structure their daily lives or how social and environmental factors influence their goals and their choices (Appelros, 2007; Haggstrom & Larsson-Lund, 2008; Mayo et al., 2002; Roth & Lovell, 2007).

The medical and rehabilitation literature has concentrated on how impairments from stroke determine activity and restrict participation (Desrosiers et al., 2006; Ostir, Smith, Smith, & Ottenbacher, 2005), but people with disabilities stress that physical, social, attitudinal, and policy barriers in their environments equally impact their choice to participate in meaningful activities (Albrecht, Seelman, & Bury, 2001; Davis, 2000; Oliver, 1990). Indeed, although all of the current models of disability recognize that environmental factors affect how people engage in their daily lives, research is lacking on how these factors influence people's levels of participation (Haggstrom & Larsson-Lund, 2008; Whiteneck et al., 2004).

1.1 Study Purpose, Research Questions

This study sought to develop an in-depth understanding of the role that choice, barriers, and facilitators play in stroke survivors' activity selection by answering two research questions:

Based on an ecological model, what are the perceived barriers and facilitators associated with the everyday choice of activities for those who have had a stroke from 1 to 6 years ago?

Are there differences and/or similarities between two activities: (1) that stroke survivors have not yet resumed or had to give up and (2) another activity they have continued?

Answers to these questions were revealed in this study.

CHAPTER 2

BACKGROUND

2.0 Introduction

This chapter begins with an explanation of how the literature was selected for review and provides a brief review of the literature. The topics of community integration, stroke, and activity are each voluminous topics. In each of these topic areas, the literature review will move from general to specific literature related to resuming activities after stroke. Section 2.2 concentrates on the definition of community reintegration as well as how activities and participation are linked to the Canadian Stroke Network definition of integration. Section 2.3 presents a general overview of activities after stroke. Section 2.4 reviews three specific factors that the literature identifies as contributing to the lack of activity after stroke: (1) disability, (2) the individual's reaction to disability, and (3) the individual's social and environmental context. Finally, Section 2.5 introduces an ecological model as a way of conceptualizing the multidimensional effects of the social and physical environment on stroke survivors' activities.

2.1 Literature Search

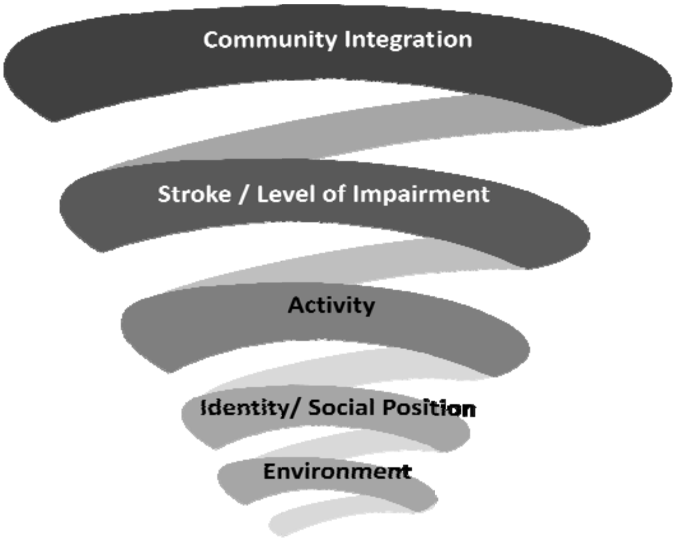
The following terms were used in the literature search, stroke and brain injury then community reintegration, re-integration, integration re-engagement, participation, quality of life, activities, and environment. Cresswell (2003) stated that in grounded theory research, "literature will serve less to set the stage" (p. 30); rather, it will help the researcher frame the research questions then become an aid to the analysis and influence the conclusion drawn as results are compared to existing evidence. To this end, the systematic literature search will be ongoing.

Initially, a broad search was performed using the Internet search engines Google and Yahoo for books, reports authored by government and stroke organizations, and the article indexes (MEDLINE, PsychInfo, CINAHL, Social Sciences Citation Index, and ERIC from 1990 to 2007). At the outset, the researcher found and reviewed over 360 articles from peer-reviewed journals as well as 14 documents from the Canadian Institutes for Health Information, Heart and Stroke Foundation, Canadian Stroke Network, and Health Canada. For other relevant material, the researcher checked references used in books and articles as well as backward and forward citation maps in the article index, Web of Science. This search revealed an additional 40 articles on community integration not found in the first search.

In the process of conducting the research, the author searched for information on theory and models on how activity, identity, and disability related to community integration. This study uses the term disability as it is used by Albrecht, Seelman, and Bury (2001) in the *Handbook of Disability Studies*. Disability is a social and biological phenomenon that exists at the intersection between: impairment (the biological condition), society's interpretation of impairment, the social effects of that interpretation, and the person's environmental context. In this study, the term disability will be used to describe social and biological disablement. The term impairment will be used to describe biological impairment. This usage acknowledges the social model definition of disability, "Limit or loss of opportunities to take part in community life because of physical and social barriers" (Altman, 2001, p. 103) and the concept of biological impairment defined as, "problems in a body function or structure as a significant deviation or loss" (WHO, 1999, p. 16, cited in Altman, 2001, p. 105)

This literature review has been iterative, moving from general to specific, as the researcher explored particular facets of the five main areas of inquiry. Figure 2.1 illustrates this process.

Figure 2.1 Iterative Literature Review Process: Integrated Elements



2.2 Community Reintegration after Stroke

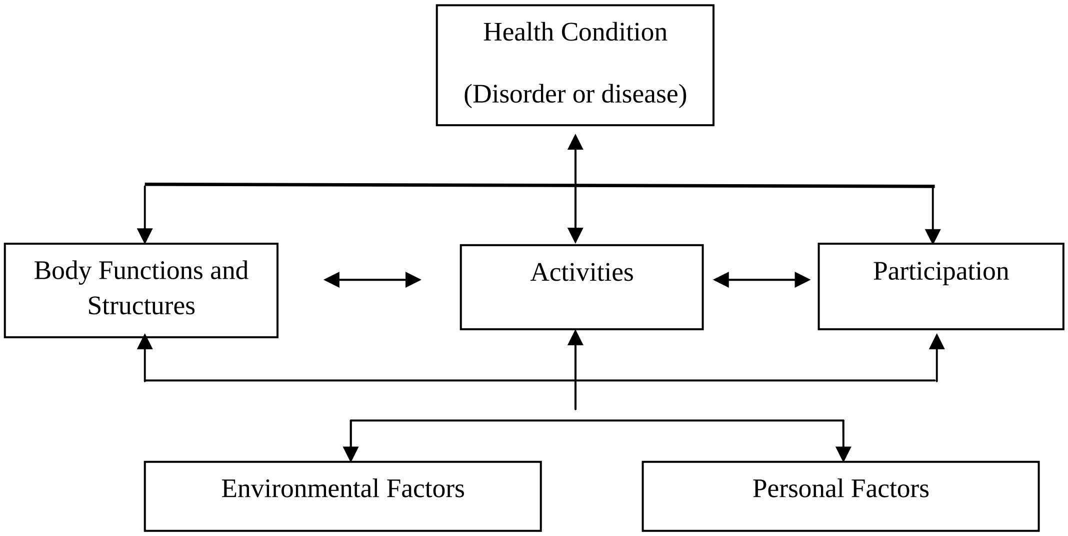
Biopyschosocial recovery from stroke can be remarkably successful for some individuals; however, for the majority of stroke survivors, maintaining functional autonomy in the community is a difficult process (Appelros, 2007; Mayo et al., 2002; Roman, 2008; Roth & Lovell, 2007). After an emergency visit, a few days in hospital, or a few weeks of in-patient rehabilitation over 80% of stroke survivors are discharged home (CIHI, 2006; Heart and Stroke Foundation of Ontario [HSFO], 2007; Lewis, Trypuc, Lindsay, O'Callaghan, & Dishaw, 2006). Even those survivors with seemingly small or mild strokes experience a significant disruption in their daily activities and functional abilities (Rochette et al., 2007). In fact, only 25% of stroke survivors recover completely (HSFO, 2007). The exact meaning of recovery and health in chronic disease, stroke, and disability is a subject of debate. Often medical professionals equate recovery with physical recovery, but people with disabilities and stroke survivors consider their psychological and social recovery equally if not more important. Vanhook (2009) completed a detailed review on this topic, the domains of stroke recovery, but suffice to say the goal of medical treatment and rehabilitation is not necessarily complete recovery or return to a pre-stroke level of functioning. However, it does include engagement in meaningful daily activity, community integration, or participation (Cardol, de Haan, van den Bos, de Jong, De Groot, 1999; HSFO, 2007; Rochette, Korner Bitensky, & Levasseur, 2006; World Health Organization [WHO] International Classification of Functioning, Disability and Health [ICF], 2001).

Community reintegration is possibly the most overlooked factor in the stroke management continuum (Bhogal, Teasell, Foley, & Speechley, 2003). Six months after discharge from stroke rehabilitation programs, one third of stroke survivors have lost the significant gains they made during their rehabilitation (Hopman & Verner, 2003; Salter, Teasell, Bhogal, & Foley, 2007); over half of stroke survivors lack meaningful daily activities (Appelros, 2007; Clarke, Marshall, Black, & Colantonio, 2002; Mayo et al., 2002; Roth & Lovell, 2007). Furthermore, the majority report significantly poorer quality of life than age-matched peers (Clarke et al., 2002; Kim, Warren, Madill, & Hadley, 1999; Salter et al., 2007).

Community Reintegration

The Canadian Stroke Network (CSN) defines community reintegration as "a process by which individuals with stroke are enabled to increase their participation in personal, family, and social roles and thereby improve their quality of life" (CSN, 2008, p. 6). The Canadian Stroke Network has recommended using the WHO ICF (2001) to measure community reintegration outcomes. This model is valuable because it considers how individuals are affected by social and environmental conditions. It uses a standard language to describe the health-related states, social participation, and personal activities. "Participation" is defined as "involvement in life situation" or the "'lived experiences' of people in the actual context in which they live" (WHO, ICF, 2001, pp. 14-15). Activities are defined as "the execution of a task or action by an individual". The following figure is a representation of the WHO ICF Model of Health, Functioning, and Disability (Figure 2.2).

Figure 2.2 WHO International Classification of Functioning (2001)



However, there are two problems with using this model to measure outcomes: (1) there is conceptual overlap between the activities and participation domains and (2) there is no subjective component in the model. First, activities are conceptualized as discrete tasks like walking a few steps or writing a cheque. Walking to the store to get groceries or paying the bills with the cheque are considered participation. It is not clear where activity ends and participation begins (Badley, 2008; Kagan et al., 2008). Some researchers have interpreted the activities category to be purely physical functioning, whereas others have assumed it includes the individual's choice, values, and assessment of their performance (Badley, 2008). Kagan and co-authors (2008), who work with stroke survivors in the community, have proposed that activities and participation should be integrated into one broad category. They pointed out that people do not distinguish between tasks, activities, and social roles. In their view, activities and participation are a continuum. Second, it is important to recognize that the ICF was designed to be an objective observational measure. It is used to classify health and health-related domains for epidemiological and population health purposes. In the original texts, the authors recognized a need to "establish links with quality of life concepts and the measurement of subjective well-being"

(World Health Organization, 2001, p. 251); however, to date, it has not been revised to include the individual's subjective description of health and function, social life, or subjective quality of life. The dichotomy between objective study and subjective experience is also present in the rehabilitation and lay perspectives of the process of community integration (Brown et al., 2004).

Community Integration: Outcome or Process

Rehabilitation is most often regarded as the process by which people increase participation in their daily activities. Consequently, in the rehabilitation literature, community integration is regarded as a rehabilitation outcome (Brown et al., 2004; McColl et al., 1998). In other words, as the result of successful medical treatment and rehabilitation interventions, the person is discharged home. To people with disabilities, discharge home is not an outcome, it is a beginning. Community integration is the product of inclusion and being a member of the community who can participate fully (Brown et al., 2004; Kagan et al., 2008). Stroke survivors regard successful community integration as return to their pre-stroke activities and lifestyles (Clarke & Black, 2005; Hafsteinsdottir & Grypdonck, 1997). The meanings of these two outcomes are different and imply quite different responses.

Concept of Activity for the Purposes this Study

This research adopts the perspective of Kagan et al. (2008) and McColl et al. (1998) that activity is "what people do" and their subjective experience of those actions. The subjective experience of "what the person does" involves their qualitative appraisal of (1) how the activity meets their goals, (2) what satisfaction they derived from doing it, and (3) how they perceived it met their performance standards. The focus of this research is whether the person's external context prevents or facilitates participation in activities. Based on studies of aging (Atchley, 1971; Atchley, 1999; Baltes & Mayer, 1999), quality of life deteriorates if an individual's environment restricts his or her personal choice of activities. For the purposes of this study, activity was defined as: "any specific action or pursuit" that participants chose to discuss.

2.3 Activities after Stroke

In the early 1980s, lack of age appropriate, meaningful activities was identified as the largest problem encountered by stroke survivors and their families (Harwood et al., 1994). At 1-year post-stroke, Holbrook and Stilbeck (1983) found three quarters of the 122 British patients they surveyed had not resumed any of the normal everyday activities they valued pre-stroke. At about the same time in Canada, Belanger, Bolduc, and Noel (1988) reported similar results; more than half of stroke survivors (n = 129) did not participate in any community activities including going to church or visiting a restaurant. It is important to note that over 60% of stroke survivors were frightened of being left alone in their own home.

In 2002, despite improving rehabilitation techniques, Mayo and colleagues still found that half of the survivors in their sample (participants n = 434 & controls n = 486) lacked “important” “meaningful” activities to fill their days. Even more recently, using the same measure as Holbrook and Stilbeck (1983), Roth and Lovell (2007) reported that about 25% of people discharged from in-patient stroke rehabilitation programs (n = 735) were active; however, the majority reported few daily or weekly activities. In fact, in their cohort of rehabilitation graduates, the most frequent activity was “doing nothing.” Even though the majority of these survivors had good functional recovery (Functional Index Measure mean = 101.07[1,2]), over half did not wash clothes (63.9%), do heavy housework (71.9%), pursue a hobby (76.7%), drive a car or travel by bus (73.2%), or read a book (64.8%). Admittedly, some of this is explained by a weakness of the FIM to distinguish between valued activities and the influence of gendered roles. Nonetheless, the results indicate that stroke survivors do have difficulty resuming activity.

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[1] Patients with admission FIM scores between 40-60 who were > 74 years were at high risk for discharge to a long-term care facility. Patients with an FIM score > 80 were discharged home (Oczkowski & Barreca, 1993).

[2] The maximum FIM score is 126.

For those recovering from stroke, returning to self-defining pre-stroke activities re-establishes their sense of identity and improves their quality of life (Amarshi, Artero, & Reid, 2006; Clarke & Black, 2005; Haggstrom & Larsson-Lund, 2008). Daily activities are integral to people's identities, they provide the context for creating meaning in their lives, and are fundamental to being human (Christiansen, 1999; Law, 2002; Millgram, 2005).

2.4 Factors that Influence Activity and Participation after Stroke

Understanding what and how factors interact to enable participation in meaningful activities should theoretically inform interventions to improve stroke survivors' quality of life (Rochette, Korner-Bitensky, & Levasseur, 2006; WHO ICF, 2001). The stroke literature pinpoints three major factors that influence participation in activities: (1) level of disability, (2) individual reaction to disability, and (3) social and physical environments.

Disability Restricts Participation

First, severity of stroke and level of impairment are factors most often related to stroke survivors' failure to resume personally meaningful activities (Clarke & Black, 2005; Rochette et al., 2007). The majority of the stroke literature has used correlational measures to demonstrate how variables such as age, functional and cognitive impairments, activities of daily living restrictions, depression, and social support deficits prevent participation or reduce community reintegration (Roberts & Counsell, 1998; Schepers, Ketelaar, Visser-Meily, Dekker, & Lindeman, 2006). Roth and Lovell (2007) correlated a score of 80 (maximum 126) on the Functional Independence Measure (FIM) with more community participation, meaning that higher FIM scores correlated with higher activity levels. In an earlier study, Segal and Schall (1994) found a much higher score of 100 was required before stroke survivors resumed activities.

Relating activity and participation to physical limitations is disputed by research that reports that functionally independent participants or those with very mild physical disability still may not be engaged in meaningful daily occupations

(Duncan et al., 1997; Mayo et al., 2002; Rochette et al., 2007). Other studies report significant improvement in participants' physical functioning without any increase in people's activity levels (Hammell et al., 2007). Conversely although physical functioning outcome measures showed physical decline 2 to 4 years post-stroke, social roles and activities remained relatively stable (Belanger, Bolduc & Noel, 1988; Rochette et al., 2007). These results indicate that physical disability alone does not prevent social role engagement.

Severity and location of stroke plus loss of physical function are the major criteria to determine rehabilitation admission and discharge destinations for patients (Timbeck & Spaulding, 2003). Measures of impairment like the Functional Independence Measure (FIM), NIH Scale, Canadian Neurological Index, Barthel Index, or Rankin Scale are used to objectively describe the person's impairment from stroke and functional independence (Dromerick, Edwards, & Diringer, 2003; Kelly-Hayes et al., 1998). To healthcare professionals, scores on these instruments are an indication of the amount of assistance individuals will require to carry out their activities of daily living. For example, Granger and colleagues (1990) found an increase of one point on the FIM score, reduced the overall personal help required by 3.38 minutes a day. Then in a 1993 follow-up study, they determined that same one point gain reduced the amount of physical help required by 2.19 minutes per day (Granger, Cotter, Hamilton, & Fiedler, 1993).

In-patient rehabilitation does reduce disability. It can raise FIM scores on average by 33% (Dodds, Martin, Stolov, & Deyo, 1993) or about 20 points (Timbeck & Spaulding, 2003). People with severe and mild strokes are often excluded from rehabilitation. Patients with mild stroke are assumed to achieve full recovery with little or no intervention (Edwards, Hahn, Baum, & Domerick, 2006). The definition of stroke severity (i.e., mild, moderate, or severe) varies between hospitals, rehabilitation centres, and research studies (Gosman-Hedstrom, Claesson, & Bolmstrand, 2008; Rochette et al., 2007). Generally, a FIM score of below 40 is considered severe, 40 to 80 or 100 as moderate, and above 80 or 100 as mild. Even with rehabilitation, individuals with severe stroke are likely to be admitted to long-term care. Oczkowski and Barreca (1993) determined that no patients with admission FIM scores below 36 were discharged home, but all patients with scores over 96 went home.

In determining which patients are referred for rehabilitation after discharge from hospitals, the scores on the FIM or Canadian Neurological Index are not the only criteria used for admission to rehabilitation. Patient motivation, patient potential, and having a family willing to care are other considerations. Black, Soltis, and Bartlett (1999) determined that having a caregiver at home is the best predictor of discharge home, not level of disability. Since much of the research does relate disability to inactivity, it is critical to consider the disability level of the study participants.

Individual Response to Disability Affects Integration

The second factor in the stroke literature that relates to participation in activities is the individual's response to disability. Some individuals view stroke as a catastrophe, where death may be preferable to disability (Murphy, Sackley, Miller, & Harwood, 2001; Slot & Berge, 2009). Some people take a very limited view of the type of activities in which a person with disability might engage; those people believe they can engage in activities only if they fully recover the function in their arm or leg (Albrecht & Devlieger; 1999; Dowswell et al., 2000). They embody the negative perceptions of their health and disability as well as create a cycle of fewer roles, social relationships, and activities (Burton, 2000; Dowswell et al., 2000). Other individuals manage to negotiate a new identity by incorporating new activities or adapting old activities to their current capacity (Becker, 1993; Becker, 1997; Clarke & Black, 2005). Albrecht and Devlieger (1999) proposed that people develop this new identity by learning to re-engage in activities with disability. Individuals respond to their situations by managing comprehensibility, manageability, and meaningfulness. "Comprehensibility" refers to an individual's sense of coherence that allows them to make sense of the chaos and ambiguity that disability now imposes upon their lives.

“Manageability” is the individual’s perception of sufficient internal and external resources to cope with the problems they encounter. “Meaningfulness” is the capacity to find significance, purpose, and motivation in daily life (Albrecht & Devlieger, 1999).

Pound and colleagues (1998) disputed loss of identity after stroke. In their study, people did not describe a lost or changed identity. Disability was a normal event classified as another difficulty in a difficult life or part of aging. This is a social constructionist view that people’s identities were not fixed; identity is created by people’s social relationships and activities as they proceed through life (Burr, 1995). Recently, several research teams have followed this line of inquiry. They note that people with stroke are socially positioned as “the other,” as someone who has lost their identity because of disability. Rather than being regarded as the same person, who has to deal with an extra-ordinary situation, people are told they are different (Ellis-Hill, Payne, & Ward, 2008; Hinojosa, Boylstein, Rittman, Hinojosa, & Faircloth, 2008).

Ellis-Hill, Payne, and Ward (2008) proposed a Life Thread Model, where stroke survivors piece together the threads of their identity by being able to resume familiar activities and roles. These authors believe that a significant part of reconstructing familiar activities and roles is how others in the person’s social context position them. Other people help to define what a person with this ability and in this social position is entitled to do (Harré & Langenhove, 1998). People actively define their identities by taking positions in relation to other people and in the social context. They take positions and assign positions to others as they negotiate power and parity (Boxer, 2002). They can accept the position that they take or are assigned or they can challenge it by rhetorically re-describing that position. For example, the doctor says to Mary, “You will not be able to work.” Mary can accept the “never work” position or she can challenge this description by asking, “Doctor, what do you mean by work? Are you saying that I can’t wash clothes?”

The effects of social positioning have been studied in relation to Alzheimer's disease but not in stroke. People with Alzheimer's have been positioned as non-persons, where they have no right to be heard (Kitwood, 1999; Sabat, 2001, 2003). The position of people with stroke cannot be described as "toxic" like people with dementia, but how they are treated socially likely does contribute to what activities stroke survivors are offered. Certainly, although it is not called positioning, the qualitative literature describes the effects of such positioning. Depersonalization (treating the diagnosis instead of the person) (Bendz, 2000); overprotection (not allowing the person to venture out independently) (Hammel, Jones, Gossett, & Morgan, 2007); and negative attitudes to recovery (Haggstrom & Larsson-Lund, 2008; Jones, Mandy, & Partridge, 2008) are all linked to less activity after stroke. Atchley (1999) pointed out that individuals do adapt to functional limitations if they choose to disengage from an activity, change activities, consolidate activity patterns, or substitute new activities. Individual wellbeing is affected only when internal or external barriers force the individual to disengage from activities; in other words when the disengagement is not of their choice.

Social and Physical Environments Impair Participation

Third, a small body of stroke literature has examined how factors in a person's environmental context—physical environment, social environment, and broad policy environment—facilitate participation. These external constraints and opportunities can directly, and indirectly, influence individual activity choices (Horgas, Wilms, & Baltes, 1998). Kim, Warren, Madill, and Hadley (1999) found that disability explained only 6% of the variance in quality of life; social support and depression explained the majority (n = 50). They suggested using a health promotion ecological model to examine how environmental and social factors interacted with biological impairments to reduce quality of life.

However, the effects of an individual's social and physical environments on their activities have been difficult to quantify (Whiteneck et al., 2004). Desrosiers et al. (2006) found environmental factors explained only 13% of the decline in activities in older adults with stroke (6 months, n = 102 and 2–4 years later, n = 66). Desrosiers et al. (2006) found little empirical evidence showing that environmental factors influenced participation. However, in a very recent study of adults over 60 (not post-stroke), Levasseur et al. (2008) did discover that people with more activity limitations perceived more environmental barriers and experienced more disruption from environmental obstacles than people without limitations. Quantitative research may not be the best way to determine the effect of the environment on how people participate. Asking stroke survivors for their perceptions and opinions may provide more valid information (Brown et al., 2004; Whiteneck et al., 2004).

Interestingly, the majority of the qualitative research on participation links external factors (e.g., social support from family and friends, accessible environments, accessible transportation, financial resources, and organizational support) with increased participation (Amarshi et al., 2006; Clarke & Black, 2005; Hammel et al., 2006; McKevitt et al., 2004). Survivors in these studies commonly reported negative attitudes toward disability, lack of information, and limited transportation. However, only Hammel, Jones, Gossett, and Morgan (2006) specifically examined stroke survivors' perceptions of environmental barriers and facilitators using participatory action research. Initially, participants in their study reported that their opportunities to participate were restricted by lack of information. When asked what they wanted to do and they attempted to engage in the activity, multi-layered and multi-level barriers presented. For example, families refused to let the survivor participate because they worried about their safety, transportation was not accessible, or public reactions to their participation were negative. Cost of programs, physical accessibility, training of staff, attitudes of staff, and facility policies were additional barriers specifically in community exercise programs (Rimmer, 2005; Rimmer, Wang, & Smith, 2008). Both Clarke and Black (2005) and White et al. (2007) specifically call for research to elucidate how formal and informal services effect clients' participation as well as people's perception of such services and the gaps in formal services.

In sum, it is critical to develop an understanding of how individuals living in the community with stroke disability choose activities and the factors that prevent or enable this. Most of the knowledge generated about activities post-stroke come from assessing an individual's difficulties performing activities of daily living (ADL) or alternatively, health-related quality of life measures that heavily weight ADL (Kessler & Egan, 2007). Using valid quantitative tools does describe the patterns and correlates of activity and aids in the comparison of study samples and findings (Casebeer & Verhoef, 1997). However, when the choice of measures focuses solely on how the individual's bodily impairments restricts activity, the research fails to capture the dynamic interactions between health conditions and social and physical environmental factors that can restrict activity choice and participation (Clarke & Black, 2005; Kagan et al., 2008). Disability activist, Lennard Davis (2000), points out that, "Disability is not so much the lack of a sense or a presence of a physical or mental impairment as it is the reception and construction of that difference…. For example lack of mobility is impairment, but an environment without ramps turns that impairment into a disability…" (p. 56).

As described earlier, social and physical environments exist at multiple levels of influence. They are difficult to conceptualize (Howard, Nieuwenhuijsen, & Saleeby, 2008; Kagan et al., 2008). Bronfenbrenner's (1979) biosocioecological model was used in this study as a framework to explore how people resume activities after stroke and the environmental factors that influence activity engagement. In this research, the use of the ecological model moved analysis beyond the individual level, exposing how individuals had to negotiate with people at other systems levels to achieve their activity goals.

2.5 Framework for Conceptualizing Environmental Factors

In 1979, Bronfenbrenner asserted that too much emphasis had been placed on individual behavior and too little on the characteristics of the environment. In his bioecological systems theory, human developmental outcomes are the result of the dynamic and reciprocal interactions between the individual and their environments at multiple levels. Bronfenbrenner’s focus is not on the individual, but on how the individual is influenced by (and copes with) the reciprocal interactions with people and systems in their environmental contexts. Multiple people, systems, and environments are interacting with and influencing individuals at any one time (Bronfenbrenner, 1979). Bronfenbrenner proposed a nested model of five systems. Briefly, the microsystem or intrapersonal level is the setting in which the individual lives. The mesosystem or interpersonal level is made up of the linked or connected microsystems. The exosystem or community level includes the government, private, and community systems that create microsystem environments. The macrosystem, also called the public policy level, is the general social-cultural context. Lastly, the chronosystem is the broad-based influence of culture and socio-historical conditions over the lifespan. A summary of characteristics is provided in Table 2.1.

Table 2.1

Bronfenbrenner’s Bioecological Systems Theory (2005)

System	Level of Influence/ Contact	Example
Microsystem	Setting in which individual lives, family, peers, neighborhood	Individual to family Individual to peers/friends
Mesosystem	Relationship between individual microsystems	Relationship between (and experience with) individual and family to friends, employment, community center, or church
Exosystem	Broader community and social settings which influence experience in meso and micro systems	Government funds recreation centers, healthcare, and public transit.
Macrosystem	Cultural context	Democracy, Social justice, Faith Group
Chronosystem	Sociohistorical conditions/ changes in person and environments over the lifespan	Baby boom, large population of adults over 55 years of age Aging population

Unfortunately, this model has not been applied in disability research or used extensively with samples from the general population (Howard, Nieuwenhuijsen, & Saleeby, 2008). Socio-ecological research or interventions that target multiple levels and utilize multiple strategies have been viewed as difficult to plan, conduct, and evaluate (Marshall & Altpeter, 2005). Health education and social marketing aimed at changing individual behavior are common health promotion interventions (Marshall & Altpeter, 2005). However, it is increasingly recognized that ecological approaches that place emphasis on how individual health is influenced by social and familial relationships, environmental situations, and broad social and cultural contexts are likely to have the broadest effects on health of populations (Smedley & Syme, 2000). Certainly, Redfern, McKevitt, and Wolfe (2006) believe that if community integration interventions for stroke are to be successful, an ecological approach is required.

2.6 Conclusions and Framework for the Research

Having something personally significant to do is the foundation to a meaningful life. Half of the people who survive stroke participate in few activities. Even those with seemingly good physical recovery do not resume activities as might be expected. From the literature on stroke, it is evident that amount and type of impairment intersects with the individual’s response to their situation, and their social and physical environment to enable participation. Generally, most stroke research has focused on how individual level factors impair participation and evaluating interventions to assist them to participate. However, few interventions (e.g., leisure, social support) delivered to survivors in the community improve quality of life or participation (Redfern et al., 2006; Teasell et al., 2007). Recently, Redfern et al. (2006) proposed using ecological model to theorize and understand the complex interactions between individuals with stroke and their environments before developing complex interventions. No record was found in the literature review of an ecological model being used to study community integration in stroke.

CHAPTER 3

METHODS AND PROCEDURES

3.0 Introduction

This chapter outlines the methods and procedures by which the data was gathered and analyzed for this study. Section 3.1 begins with an overview of the theoretical framework used to underpin the study. Section 3.2 provides a description of methods of selecting participants as well as the procedures used to gather and analyze the data. Section 3.3 ends with the measures used to ensure rigor and trustworthiness of the data gathering process.

3.1 Theoretical Framework

“Epistemological reflexivity” asks the researcher to reflect on the nature of knowledge and how we believe knowledge is revealed. The choice of research design implies underlying theoretical assumptions and follows particular paradigms (Morse & Richards, 2002). A paradigm is “a set of beliefs, a set of assumptions we make that serve as touch stones in guiding our thoughts and activities” (Shkedi, 2005, p. 18). Both epistemological assumptions and beliefs have theoretical implications for defining, answering, and investigating research questions. For this study, Clarke’s (2005) “Situational Analysis, Grounded Theory after the Postmodern Turn,” was used; however, this was not how the study began. This section provides some background on the process of choosing grounded theory, provides the rationale for changing from Charmaz’s (2007) constructivist grounded theory to situational analysis (Clarke, 2005), and then offers a brief overview of situational analysis and importance in this research project.

Grounded Theory

The research started using grounded theory as described by (Charmaz, 2007; Glaser & Strauss, 1967; Strauss & Corbin, 1998). The researcher chose grounded theory as it provides an opportunity to develop theory inductively from the reality of people in the situation. From a literature search, the dominant approach in stroke research has been the medical model and quantitative measures. Ellis-Hill, Payne, and Ward (2008) charge that this approach is largely responsible for the significant gap in understanding motivations of stroke survivors.

In the 1960s, social science research moved towards positivistic methodologies and quantification. This was based on the idea that scientists could discover the truth and make judgments about the nature of reality based on objective scientific evidence (Burr, 1995). In this paradigm, the “quality of human experience” was described by “quantifiable variables” (Charmaz, 2007). Qualitative methods—and grounded theory in particular—challenged the positivist belief that an objective external truth determined by objective scientific observers exists. Grounded theory draws on the work of symbolic interaction. In the view of symbolic interaction, people construct their own and others’ identities from social interactions in everyday encounters (Burr, 1995; Charmaz, 2007). Thus, there is not one truth but many truths dependent upon the situation and people’s social interactions.

Grounded theory is a “systematic, qualitative process used to generate a theory that explains, at a broad conceptual level, a process, an action, or interaction about a substantive topic" (Cresswell, 2002, p. 439). Based in symbolic interactionism and social constructionism, Glaser and Strauss (1967) proposed that human subjective and social meanings relied on the use of language and emerged through social actions. Therefore, the basic social processes in which humans engaged should be studied inductively from the perspective of the participants. Glaser and Strauss (1967) and later Strauss and Corbin (1998) legitimized qualitative research as a credible methodological approach to develop theory (Charmaz, 2007). “Theory” as defined by Strauss and Corbin (1998) “denotes a set of well developed categories (e.g., themes, concepts) that are systematically inter-related through statements of relationship to form a theoretical framework that explains some relevant social, psychological, educational, nursing or other phenomenon" (p. 22). Grounded theory assumes: (1) that reality is constructed and reconstructed in social processes, (2) that meaning is created and modified through reciprocal interpretive process as people deal with others, and (3) that sense is created through characterizing/ classifying exchanges of people in social interaction (Glaser & Strauss, 1967; Morse & Richards, 2002; Suddaby, 2007). While these principles remain common, grounded theory methods have taken different forms, mainly around the position and neutrality of the researcher.

The classic work of Glaser and Strauss (1967) assumes the scientific observer is completely separate from the participants and that theory emerges entirely from the data. Glaser and Strauss's standpoints have since diverged. Recently, Glaser (1998, 2002) has emphasized that an objective, neutral observer researcher stance is critical to grounded theory methodology. In his view, the grounded theory and the named concepts emanating from the data are not an understanding of the worldview of the research participants, but a theoretical understanding of the social processes (Glaser, 2002). In fact, in Glaser's view the participants themselves might not understand the social processes. Conversely, Strauss and Corbin (1998) want to ensure the participant's voice is represented; however, they too believe the observer should remain neutral. They have developed technical research procedures to guide unbiased data collection and analysis. Researchers are expected to choose between Glaser's (2002) or Strauss and Corbin's (1998) methodological procedures (Charmaz, 2007).

Charmaz (2007) suggested that both Glaser (2002) and Strauss and Corbin's (1998) epistemological leanings are positivistic and the researcher as observer does not align with current post-modernist or constructivist worldviews. In her view, grounded theory does not emerge from the data nor is it objective; rather "any theoretical rendering offers an interpretive portrayal of the studied world and not an exact picture of it" (p. 10). She believes that grounded theory is constructed through the history and present involvement of both researcher and those researched. Certainly, there is ample evidence to support her position that all research is socially constructed. For example, what research is funded, what researchers choose to study, how the research questions are posed, and how those researched are positioned in the results are all influenced by social and cultural discourses (Charmaz, 2007; Clarke, 2005; Langenhove & Harré, 1999), a position fits with this researcher's beliefs. Therefore, this study was guided by Charmaz's (2007) theoretical position on constructivist grounded theory methods.

It is important to note that regardless ones views on researcher objectivity, these grounded theory methodologists (Charmaz, 2007; Clarke, 2005; Glaser, 2002; Glaser & Strauss, 1967; Strauss & Corbin, 1998) use similar procedures to develop new theory. These procedures include collecting and analyzing data simultaneously throughout the research process; identifying causal conditions, action strategies, context, intervening conditions, and relationships in each piece of data and applying codes (naming); questioning if there are alternate ways to view the data; developing categories and systematically verifying the conceptions through repeatedly comparing codes in each successive piece of data with previously identified concepts; and laying out the theory that explains all of the cases or accounts for deviant/outlying cases (Strauss & Corbin, 1990).

As the researcher worked to develop an understanding of study data using these grounded theory methods, the different forms of grounded theory were confounding; in particular, how different grounded theory methods treat variation in the data and the context in which the data is created. The researcher believed different interpretations of the position of the researcher would be critical. However, the researcher had difficulty with abstracting and laying out a theory that accounted for all of the cases. Variations in level of stroke disability, people's viewpoints, and environmental situations made it difficult for the researcher to see anything other than disability as a barrier to activity. After the first four interviews, with each successive layer of categorizing, the researcher believed the problem related to how the questions focused on individual actions that the social and environmental context was stripped out during analysis. The questions being asked were the following: (1) What processes or actions are happening? (2) How does this process develop? (3) What are the underlying assumptions of the participants? (4) What might that behavior or assumptions indicate? and (5) What are the consequences of the actions/ processes? For this researcher, answering these questions seemed to result in categories related to individual actions rather than categories related to the individual's social context. The researcher went back to the different grounded theory textbooks to determine if there was some way through this impasse.

Grounded Theory to Situational Analysis

Traditional grounded theory, especially as promoted by Glaser, seeks a scientifically constructed universal explanation of the data. In Glaser's view, time, situation, and people are to be incorporated into a general theory; any variants are treated as outliers that must be explained away (Glaser, 2003). Glaser believes that grounded theory like positivist deductive theory should be able to universally explain the chosen research problem regardless of the people and situation (Glaser, 2002). In contrast, Charmaz recommended analyzing how research participants' actions are constructed in the social contexts, "hidden positions, networks, situations, and relationships" (Charmaz, 2007, p. 130). Charmaz (2007) contends that variation must be documented, and that through the research process we gain the data and knowledge to make visible the differences between people, along with the "hierarchies of power, communication, and opportunity" that maintain the systems (Charmaz, p. 130). Even using Charmaz's techniques as a guide, the researcher still felt that as interviews were being coded that the study was missing or muting the participant's environmental context. Coming from a disability studies background, the researcher explicitly wanted to understand the ways in which the individual and his or her social and physical environment interacted to prevent or help them resume activities. Clarke (2005) developed the situational analysis method to clarify exactly how the multiple discourses, actions, and elements in the situation could be integrated into grounded theory. Rather than explaining variation away, Clarke assumes there are "differences and multiplicities” that researchers need to explicitly map and represent (Clarke, 2005, p. 19).

Situational Analysis

Clarke (2005) recognized that grounded theory has concentrated on basic social processes—the actions of individuals in their social relationships. But she believed the context in which those processes and actions are situated has been neglected. She shifts the focus from social process/ action to the social ecology of the situation by explicitly searching for how people’s actions and choices are influenced by broader social world context. She specifically lays out six suggestions for ensuring that the social and physical environment is included in grounded theory analysis:

1. Centering researcher attention and analysis on the “situation” as the site of the action;
2. Acknowledging the embodied nature of knowledge that is produced through a constructed research process of those who are studied and those doing the studying;
3. Recognizing, accepting, and speaking to the differences rather than aggregating heterogeneity;
4. Affirming the need for integrated analysis and the insufficiency of formal theory;
5. Mapping the context, social worlds, social positions, and social and physical environments; and
6. Expanding the domains of grounded theory research by explicitly mapping the discourses that historically underpins and currently order our perceptions, and how these are used to construct the situation.

Clarke’s (2005) research and analysis methods included all of the traditional grounded theory techniques described earlier (e.g., theoretical sampling, coding, and memoing), but she added situational, social worlds/ arenas, and positional mapping. “Social worlds/ arenas” (SW/A) are the contexts in which people inhabit, actions occur, and processes evolve. SW/A analysis was originally conceived by Strauss (1978, 1993) who described an arena as the “interaction by social worlds around issues—where actions concerning these are being debated, fought out, negotiated, manipulated, and even coerced within and among the social worlds” (p. 226). Strauss introduced the concept of negotiated order to explain patterns of actions at multiple levels of analysis in any arena. In his view, negotiation was central to the social order in which people live. He stressed that negotiation was not exclusively between individuals, but must be examined within institutional and power relationships in the individual’s wider structural context. “Negotiated order” is the result of actions and social interactions that produce a dynamic social order. Much of Strauss’s work (Strauss & Corbin, 1998) dealt with the people’s work negotiating the healthcare arena. While Strauss and Corbin advocated for inclusion of the situation in grounded theory analysis, they concentrated on individual-level negotiations rather than negotiations with other people in the broader ecological context. For example, how cultural discourses, institutional regulations, and structural conditions affect patients’ negotiations with healthcare settings is neglected. Clarke (2005) insisted that these “conditions of the situation are in the situation…they are constitutive of it” not merely framing it (p. 71). This was a crucial understanding for this researcher. Situational analysis includes the following elements:

1. Individual humans;
2. Collective human elements, like nurses’, patient care institutions, and private insurers;
3. Discursive constructions of human elements (e.g., patients as needy or physicians as unavailable);
4. Non-human elements like cost containment, technology, or clinical trials;
5. Discursive constructions of non human actants (e.g., medical technologies as lifesaving or evidence-based care);
6. Silent or implicated actors;
7. Spatial elements, such as local and regional variations in rural/ urban, men/ women, or distribution of patients in a hospital;

8. Political/ economic elements, such as rising costs of hospitalization or concepts of individualism;
9. Related historical, narrative, or visual discourses (e.g., women as reproductive bodies, duty to be healthy, or marvels of modern medicine);
10. Major issues (usually contested), prevention versus treatment, work restructuring, health system, community, or personal funding.

Using these structural conditions as a sensitizing framework, Clarke (2005) recommended that researchers use traditional grounded theory methods of coding, categorizing, memoing, and theorizing and then three mapping strategies, situational maps, social world/ arena maps, and positional maps. The goal is to explicate all the elements and the relationships between the elements in the chosen research arena. Situational maps lay out all the elements in the research situation. Social world/arena maps describe relationships between situational map elements. Positional maps look at discourses in the arena and how they help to construct and create the situations.

For the purposes of this study, situational mapping was used, but it is worth noting that these maps of the situation are far from complete for two reasons. First, Clarke (2005) provided a general overview of how to map situations, but her technique is fairly complex. Other researchers using the same methodology have encountered similar problems (K. Olson, personal communication, June, 2009). Secondly, Clarke used viewpoints of stakeholders from multiple influence levels. In the present study, the researcher has talked only to individuals who were trying to resume activities, not to people working in the healthcare system or in the community at the mesosystem level of influence, nor to policymakers at the exosystem level of influence. Study participants for the present study would be negotiating with institutions in these systems levels.

3.2 Study Purpose and Objective

The purpose of this study was to develop an in-depth understanding of the role that choice, barriers, and facilitators play in stroke survivors' activity selection. The objective was to answer two research questions:

Based on an ecological model, what are the perceived barriers and facilitators associated with the everyday choice of activities, of those who have had a stroke from 1 to 6 years ago?

Are there differences and/or similarities between two activities (one that stroke survivors have not yet resumed or had to give up) and another activity (that they have continued)?

3.3 Descriptions of the Methods Used

Data Collection Procedures

Participants

Participants for this study were selected using the following inclusion and exclusion criteria:

Inclusion criteria

1. Between 50 to 70 years of age;
2. Able to independently answer interview questions (without a proxy);
3. Living in the community in the greater Edmonton area; and
4. Able to understand and speak English.

Exclusion criteria

1. Living in an institution;
2. More than 6 years post-stroke;
3. Not proficient in English;
4. Other neurodegenerative diseases (e.g., Alzheimer's or Parkinson's); and
5. Severe aphasia, severe depression, or severe cognitive impairment.

The rational for these inclusion and exclusion criteria were as follows:

The age group 50 to 70 years of age was selected because research on aging suggests that activities outside the home generally decrease in people over age 75 (Atchley, 1971, 1999; Baltes & Mayer, 1999); younger stroke survivors experience a number of barriers not experienced by older individuals (Stone, 2005); and once cause of stroke is determined and treatment has been successful, younger people are likely to survive for many years (personal communication, Dr. Antoine Hakim, April, 2007).

Time after stroke was restricted to 1 to 6 years because survivors' health is usually stable at this time (Hakim, 2007). This study is concerned with resumption of activities by stroke survivors discharged into the community. The activity choices of people admitted into institutional care may differ. The locale in which people reside (either rural or urban) can influence activity choices. The greater Edmonton area was selected for this study.

Stroke survivors with neurodegenerative diseases, severe aphasia, severe depression, or severe cognitive impairment were excluded because these conditions are sufficient to compromise participation (Clarke & Black, 2005; Kim, Warren Madill & Hadley, 1999). Understanding participants is critical to qualitative research (Creswell, 2003). The researcher speaks English only; therefore, non-English speakers were excluded.

Participant Recruitment

After receiving ethics approval from the University of Alberta Health Research Ethics Board, Panel B, the researcher also sought approval from the Northern Alberta Clinical Trials and Research Centre (NACTRC) to be able to distribute flyers and posters to Alberta Health Services facilities like the Glenrose Stroke Rehabilitation Outpatient programs, Community Rehabilitation Integrated Services (CRIS), or homecare. Packets were assembled with letters to introduce the research, an abstract of the research proposal, and individual program contacts (e.g., Stroke Outpatient Program, Recreation Therapy Program); packets were mailed to the research coordinators at the Glenrose Rehabilitation Hospital, CRIS, and Home Living Programs (Appendix A, Letter Seeking Approval to Display Poster and Distribute Flyers; Appendix B, Abstract of Research Proposal). The study received approval from the Glenrose Rehabilitation Hospital and CRIS.

The researcher delivered letters about the project to the research coordinator at the Steadward Centre and executive directors of NABIS, Networks, and the Edmonton Stroke Recovery Association. Posters (Appendix C, Recruitment Poster) were displayed at the Steadward Centre, NABIS, and Networks. Staff or volunteers at these community agencies distributed the flyer to clients that met the recruitment criteria. People interested in participating in the study were asked to contact the researcher by phone.

Throughout the research, participants were recruited based on theoretical sampling (Charmaz, 2007). Initially, the researcher specifically wanted to delineate the properties of disability in relation to activity. Therefore, the researcher talked to staff and volunteers to specify that participants with a range of disabilities from stroke were desired. After the fifth interview, the research sought to find participants with less visible impairment and different family living arrangements to try and clarify how disability, families, and community institutions related to the process of resuming activities. As the researcher talked to staff in community agencies, she asked if they knew of stroke survivors who had gone back to work or had little visible impairment. Staff was asked if they could provide these survivors with information on the study.

Most participants contacted the researcher after they had two or more exposures to publicity about the research. For example, the staff from an agency gave them a flyer and then they saw a poster, or they saw the poster in two locations. The first participant called the researcher to participate in the Edmonton site of the Canadian Stroke Network research project, Getting On with the Rest of your Life after Stroke[3]. Recruitment for that study was complete, so the researcher asked the caller if she would like to participate in this study. The second study participant saw a poster at a physiotherapy practice and at the Glenrose. Mr. D’s Skills for Community Living Worker gave a flyer to him; he talked to the researcher at the Northern Alberta Brain Injury Association conference in April, and then contacted the researcher after seeing the poster at the Steadward Centre. When the researcher spoke at a Stroke Recovery Association Meeting, Mr. E asked if he was eligible for the research. Mr. F’s Skills for Community Living Worker gave him a poster and he called the researcher three weeks later. Mr. G saw a poster at the secondary prevention clinic. Mr. H said someone at the Glenrose mentioned the study to him and then he met the researcher at the Stroke Recovery Association picnic in June. He called the researcher in early July. Mr. I and Mrs. J contacted the researcher after seeing the poster.

The researcher provided details of the study, answered potential participant’s questions, and then arranged a time and place for the interview (Appendix D, Telephone Recruitment Script). Potential participants were offered the choice of their home, a University of Alberta office, or another location of their choice. In total, 10 people were interviewed for this study. Three people chose a coffee shop or restaurant near their home; seven preferred to be interviewed in their own home. One participant was excluded from the study. In the prescreening interview, he said he met the criteria. However, he was 72 years of age. After this experience, the researcher specifically asked potential participants about criteria (e.g., In what year did you have your stroke? In what year were you born?) rather than generally (e.g., So you saw the poster, and you are 1 to 6 years post-stroke?) Table 3.1 presents the demographics, participant interview site, and recruitment source of study participants.

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[3] Research project funded by the Canadian Stroke Network. The Edmonton project at the Edmonton General hospital is one of 7 sites across Canada. Principal Investigator is Dr. Nancy Mayo

Table 3.1 Demographic, Interview Site, and Recruitment Source of Study Participants

Participant	Demographics	Years since stroke	Interview site	Recruitment source
Mrs. B	Married, 53	3	Tim Horton's Coffee Shop	Phoned for Getting on Research Program
Mrs. C	Married, 53	2	Participant's home	Physiotherapy/ Glenrose
Mr. D	Divorced, 58	4	Participant's home	Skills for Community Living/ Steadward
Mr. E	Married, 59	6	Participant's home	Stroke Recovery Association
Mr. F	Married, 61	5	Participant's home	Skills for Community Living
Mr. G	Separated, 58	1	Tim Horton's Coffee Shop	Stroke Prevention Clinic
Mr. H	Single, 59	2	Tim Horton's Coffee Shop	Glenrose Hospital and Stroke Recovery Association
Mr. I	Married, 64	1.5	Participant's home	Edmonton Hyperbaric and contact with Getting On participant
Mrs. J	Married, 59	1.5	Participant's home	Steadward Centre

Procedures

The participants were assigned an identification code to protect their identities. Throughout the study, participants are identified by this code to maintain their confidentiality when reporting and discussing the findings of the study. Informed consent was obtained from all study participants before initiating interviews (Appendix E, Informed Consent). As a small token of appreciation, participants were given a $5 Canadian coffee shop gift card. The researcher used a semi-structured interview guide (Appendix F, Semi-structured Interview Guide) and demographic information form (Appendix G, Demographic Information Form) in all the interviews. The interview guide was modified before each interview to look for variation in the processes and the categories that were evolving from the preceding interviews (Charmaz, 2007).

Interview process

Consistently, in each interview, people were asked to tell the researcher about their experiences in an activity they had resumed and then about an activity they had yet to resume, or had difficulty resuming. Rather than using such phrases as “have not resumed” or “been unable to do,” the researcher specifically chose to use the words, “have yet to resume” because survivors have reported that they are told to be realistic about their disability status or that they will never resume an activity (Wiles, Pain, Buckland, & McClelland, 1998). Additionally, this choice of language may have helped people to focus on how their physical and social environment affected participation in activities rather than how their disability prevented them from activities. During each interview, the researcher checked assumptions with subjects, reflected back what participants had said, asked them to explain, or asked for more detail (Rubin & Rubin, 2006). At the end of each interview, participants were told that they could contact the researcher by phone or e-mail if they wanted to add to the interview. They were also asked if the researcher could contact them for further information once the interview had been transcribed, and if they wanted an abstract of the completed research. Interviews lasted 45 minutes to 2 hours and were transcribed verbatim.

Personal Communications

Four participants provided more information, two contacted the researcher by phone with information on helpful community services, one e-mailed his story, and another person e-mailed to ask if any clarification was needed.

Researcher Field Notes, Memos, and Reflections on the Research Process

Field notes were considered as data. At the end of each interview field notes on the setting, the interview process, and impressions of the data and interview were compiled. The field notes were considered as data. Additionally, a reflective interview analysis was conducted (Appendix H, Interview Analysis). The researcher reviewed initial impressions once the interview had been transcribed (Roulston, deMarrais, & Lewis, 2003). Explicit reflection on the interview process and data in the interview allowed the researcher to examine the information shared by the stroke survivors, reflect on the researcher's role in the interview, and think about how the interview process could be improved. The researcher's husband had a stroke in 1997. Throughout the interview process, the researcher was very aware of her experience with stroke and how this might influence the questions asked. The researcher used the interview reflections to review how her experience affected the interview process. The researcher chose to answer questions about her husband as honestly and openly as possible while ensuring that participants in the research understood that what the researcher was looking for was their experience.

3.4 Data Analysis

Descriptive statistics were used to analyze the participants' demographic and clinical characteristics. These statistics are derived from the demographic data collected and the participants' own account of their disability resulting from stroke. The qualitative data, interviews with participants, and the researcher's field notes, were analyzed using grounded theory methods (Clarke, 2005; Charmaz, 2007; Scott & Howell, 2008) and Clarke's (2005) situational analysis methods. The interviews were transcribed in Microsoft Word.™ The researcher reviewed the transcribed interviews for accuracy, transferred them into a two-column table, and then numbered each change in speaker.

Open, Selective, and Theoretical Coding

The field notes and interviews were coded by thinking about what the participants were saying, in their own words, when and in what situations it related to resuming or not resuming an activity, and the consequences (Clarke, 2005; Charmaz, 2007; Scott & Howell, 2008). Like most beginning researchers, the researcher for this study had many codes and needed an efficient way of handling them. A database was created using the features in Microsoft Word.™ The codes were transferred from the interview to tables, but with a hyperlink to the table and to any memos. From the initial coding, categories were developed by importing the initial codes into a conditional relationship guide (Scott & Howell, 2008). Essentially, this is a table with columns for the category, and then simple sensitizing questions describing the category (i.e., what, when, where, why, how, and consequence). Some initial codes were elevated to the major category field on the far left of the table and relegated other codes into subcategories. An example of open coding from the first interview is shown in Table 3.2.

Table 3.2 Example of Conditional Relationship Guide

Category	What is the category (use the participants' words)	When does the category occur? During	Where? In what situation	Why? Because	How does the category occur?	Consequences
People Healthcare professionals	OT at Glenrose "It was awesome" Line 213 2B	Give you all kinds of things you could do	Therapy	Return to previous activities Adaptation	Ability to do for herself	Choice Independent
People/ General public	"and the girls are really good" Line 32 2B	one of the crowd normal ordinary	Golf Pilates	"Don't look at me like there's something different." Line 34 2B	Regular activities	Encouraging "Don't feel like there's something wrong" Line 34 2B

The analysis process was far from linear. Codes would often fit in more than one category and were moved around many times during the analysis process. As delineated earlier, after using this process the researcher felt that in categorizing, the context in which the action occurred was being removed; therefore, the researcher decided to add Clarke's situational analysis methodology (Clarke, 2005).

Situational Mapping

The researcher returned to all the interviews and used Clarke's sensitizing question: "How do these conditions appear—make themselves felt as consequential—inside the empirical situation under examination?" (Clarke, 2005, p. 72). The elements in the interview were mapped using Clarke's abstract situational map. The researcher identified the "human elements" (e.g., individuals, groups, organizations, and institutions), the "non human elements" (e.g., accessibility, adaptive equipment, wait times), and "discursive constructions" (e.g., an aging population, stroke as disease of the old). The researcher wrote memos to tell how the various elements from each level of influence related to participants' activities, facilitators and barriers to activity and activity choice, and how this related to resuming or not resuming particular activities. These elements were imported into the conditional relationship table. Then from the mapping, memoing, and the conditional relationship guide, two coding matrices were developed: one for the processes of resuming activities and the other for difficulty resuming activities. The table was based on Scott and Howell's (2008) reflective coding matrix. The researcher compared how the processes of resuming activity related to the processes of difficulty resuming activity including: (1) properties of each process, (2) relationship to context, and (3) the consequences and outcome of the process.

The researcher constantly returned to earlier interviews to refine the mapping, memoing, and defining of categories. As this process was used, the researcher was aware that while it may help to build theory, it may also "force moving, data and analysis in pre-established" directions (Charmaz, 2007, p. 118). To avoid this, the researcher used the participants' own language in the coding, kept reflecting on the data, and asked if this is what the participants were relating. In the final analysis the researcher did the following: (1) related categories to each level of influence, microsystem (i.e., individual, family and friends), the mesosystem (i.e., institutional levels), and the exosystem (i.e., policy levels), (2) distilled findings into a theory of resuming activities after stroke, and (3) compared similarities and differences between resumed and non-resumed activities.

3.5 Main Ethical Issues

This study received ethics approval from the University of Alberta Health Research Ethics Board. People with severe cognitive impairment or aphasia were excluded from the study. All participants contacted the researcher themselves and were competent (in this researcher's estimation) to give informed consent. Six of the nine people interviewed had left hemisphere strokes and mild aphasia. The researcher has received training in supported communication at the Aphasia Centre of Ottawa (2004) and recently (September, 2008) from the Aphasia Institute in Toronto. By the exclusion criteria, people who required supported communication would be considered severe and would have been excluded from participating in this study. The researcher believed that she was capable of determining if participants were able to discuss their daily activities. The issue did not arise. The participants who reported they had aphasia were able to communicate well.

All interview data was transcribed by the researcher and only the researcher and the thesis supervisor had access to the data. Participants were identified by codes and in any publications that may follow; their anonymity will continue to be preserved. In publications or presentations, any identifying information will not be used to protect the participant's anonymity (e.g., Mr. E's profession). In this thesis, the quotes are verbatim. In publications, extraneous language will be removed to make the quote more readable.

At the completion of each interview, participants were asked if they would like results of the study. Several requested the abstract. After thesis approval, the abstract will be mailed to participants who requested this.

3.6 Rigour of the Data: Trustworthiness

Rigour of qualitative research, whether it has value, truth and is applicable are assessed through the criteria of trustworthiness, credibility, dependability, and confirmability (Morse & Richards, 2002). Trustworthiness answers the question "Does this research demonstrate evidence of critical appraisal?" Credibility answers the question, “Do the results of this research reflect the experience of the participants or the context in a believable way?” Dependability answers the question, “Does this research describe the context? Confirmability describes the degree to which others can confirm or corroborate results (Whittemore, Chase, & Mandle, 2001, p. 534). Reflexivity attends to researcher bias.

Consistent Data Collection

Morse and Richards (2002) and Suddaby (2006) recommend that researchers know their grounded theory method and use it consistently throughout the research process. This enables scrutiny of the methodological and theoretical decisions made throughout the research process so that another researcher looking at the data and the audit trail could understand how this researcher came to these conclusions. The phenomenon of interest as opposed to the researcher interest or bias should be described by the data. This researcher was aware that because she had a family member with stroke she had to be careful to not to force her experience into the data collection or data analysis. Several techniques were used in this study to address credibility of the findings.

The first step to credibility and dependability is ensuring rigor in the design and data collection phase (Morse & Richards, 2002). The researcher designed a consistent data collection process. Before each interview, the researcher reviewed any participant data recorded in the field notes from the telephone contact and added possible questions into the semi-structured interview guide. The researcher asked participants if the interview could be recorded on a digital recorder. Audio recording is a reliable way of capturing participant data (Morse & Richards, 2002). As soon as the participant selected their activities, the researcher related them to home or community on the semi-structured interview guide then used the guide to ask about planning the activity, getting to the activity, and help with activity. As the participant talked about planning, getting to, and doing (or being unable to plan, get to, or do) the researcher would probe around the themes of people involved, information and knowledge of activity, social and physical environmental facilitators and barriers, and types of services and support the participant required. While the researcher used the interview guide, she was open to what participants were saying. In grounded theory, knowledge and background does not mean the researcher goes looking for information to fit pre-conceived frameworks or knowledge (Morse & Richards, 2002).

Member checking

In this research, member checking was done during an interview. Member checking can be done during the interview process, at the conclusion of the study, or both to increase the credibility and validity of a qualitative study (Rubin & Rubin, 2006). The researcher restated what the participant said and then specifically asked if that was their experience or if the researcher understood the participants intended meaning.

Field notes, interview analysis

After each interview, field notes were recorded, the interviews were transcribed verbatim and an interview analysis (Appendix H) was done to ensure consistent data quality. Looking at the transcribed interview data and answering interview analysis questions enabled the researcher to improve interview technique and ensured that the data collected related to the research questions. Questions such as, "How did you do in building rapport with the participant?" and "Did you evaluate the participants' responses to the questions within the interview?" directed the researcher toward ascertaining if the researcher's understanding was the participant's. The interview analysis results were shared with thesis supervisor. Field notes provided context for this researcher. When constantly compared with the interview data, the researcher is grounded in different forms of data (Morse & Richards, 2002).

Data Analysis

Clarke (2005) and Glaser (2002a) emphasized researchers can avoid bias and ensure the results reflect the experience of the participants by analyzing the data using good grounded theory techniques. The data in this study was analyzed using traditional grounded theory coding, constant comparison, and memoing. The data was also mapped (Clarke, 2005).

Line by line open coding

To ensure portrayal of the participants or descriptive validity (Bell & Howell, 2008), open coding of the interviews was done line by line and the categories were transferred to the conditional relationship guide (Bell & Howell, 2008). The sensitizing questions in the conditional relationship guide helped the researcher describe the open codes and compare the instances from one participant to another. To keep the participants in the researchers focus, as suggested by Bell & Howell (2008) and Charmaz (2007) the participants own words were used for open coding.

Constant comparison

Constant comparison, working back and forth from the original data to coding keeps the researcher grounded in the data (Morse & Richards, 2002). The researcher followed Glaser (2002b) and Clarke's (2005) recommendations to keep asking what category the incidents indicate and what else might be going on in the situation. Mapping the data and Clarke's sensitizing questions helped this researcher to visualize how categories were comparable and opened up new ways of thinking about the data. The researcher constantly compared the data, moving back and forth from codes, interview data, field note data, maps, and memos. Sensitizing questions from Bell and Howell (2008) and Clarke (2005) were used to question the data in different ways.

Memoing

Memoing describes the codes and categories. It helps to connect and "dimensionalize" the categories; explains the processes fully (Morse & Richards, 2002, p. 138). This researcher recorded the memos in the field notes diary, and on the printed transcripts so that they were close to the raw data. These memos were transferred with the codes into the conditional relationship guide. The memos became a road map that linked the data and validated the comparisons. This helps the researcher avoid reporting that a category “appeared” or the theory “emerged” (Morse & Richards, 2002, p. 139).

Field notes

The researcher used a notebook to record field notes and memos about study. Immediately after the interviews, the researcher spent thirty minutes to one hour recording her impressions of the interview and questions to be reviewed. These chronological written notes from the first phone contact explained some of the interview data, produced codes, and helped the researcher to maintain an audit trail. Research decisions were recorded in the field notes.

Audit Trail of Data Collection and Analysis

An audit trail of research was maintained. In addition to the field notes, all interviews, memos, and analysis notes were printed and kept in a three ring binder. Analysis of the data was done consistently using the same format. Open coding was done using the conditional relationship guide (Bell & Howell, 2008), situational analysis mapping, and situational analysis sensitizing questions (Clarke, 2005). Then, the reflective coding matrix was used to guide selective and theoretical coding (Bell & Howell, 2008). These were printed and the current version was carried with field notes. These tools and the notes on research decisions made the data analysis process explicit. Although another researcher may not come to the same conclusions as the first researcher, an audit trail enables them to understand the conclusions (Morse & Richards, 2002).

Investigator Responsiveness

Morse and Richards (2002) caution researchers to be responsive to strategies that are not working. They recommend that when data analysis is stagnant, “the solution is to step back and consider why the data are not fruitful” (Morse & Richards, 2002, p. 174). When this happened in this study, the researcher stepped back, stopped data collection, and searched for other strategies in the literature.

Discussions with Thesis Supervisor

Interview analysis, situational mapping, coding matrices, and major themes were discussed with researcher's thesis supervisor. For example, the decision to exclude the first interview, utilizing Clarke's situational analysis in the analysis, while ensuring that themes were based on research questions and grounded in the data were reviewed. Additionally, after the data analysis chapter was read by the supervisor, the researcher's conclusions and alternative explanations were examined. Morse and Richards (2002) encourage collaboration to affirm trustworthy data.

Comparison with Published Literature

Triangulation with other studies is "a final step to ensuring validity" (Morse & Richards, p. 177). The similarities and differences between the results of this study on resuming activities after stroke were compared and contrasted with Clarke and Black (2005), Haggstrom and Larsson-Lund (2008), and Hammel et al. (2007) studies. These studies all acknowledge that inactivity is related to environmental factors, but with the exception of Hammel et al. (2007) did not explore environmental factors specifically. Hammel and colleagues (2007) related inactivity directly to the individual experience of the environment, for example physically inaccessible space or lack of transportation. The use of the ecological model enabled a broader analysis; it revealed how the facilitators and barriers threaded through various systems levels.

Ultimately, the most reliable indication of trustworthiness is if the participants and other stroke survivors agree that this research represents their experience of resuming activities.

Researcher Reflexivity

This researcher has taken the feminist social constructionist standpoint that the researcher is not objective; that the researcher's knowledge and background will shape the interpretation (Burr, 1995). The researcher used reflection throughout the study and recorded how that knowledge might have influenced the study in a researcher journal and in memos. Glaser (2002a) recommends that researchers bracket (or put aside) their knowledge and understandings especially during data collection. Clarke (2005) and Charmaz (2007) disagree. They recognize that researchers have done extensive literature searches as part of their research proposal and have preconceived notions about the topic. They suggest the researcher acknowledge their understanding, but reflect on how this understanding, their power, and their subject position affects the study. Researcher reflexivity is the researcher's personal awareness of their beliefs, understanding of the nature of knowledge, and how those factors affect the research process (Morse & Richards, 2002). It is now considered standard practice for researchers to inform their audience of the possible bias and to use reflection to manage that bias and subjectivity (Piantanida & Garman, 1999).

Reflexivity in writing the proposal

At this stage, the researcher reviewed the literature on social construction and researcher standpoint (Burr, 1995; Harré & van Langenhove, 1999; Orbe, 1998). Then, to ensure that it was an explicit practice, the researcher thought and journaled about the pros and cons of how her knowledge might affect the research and what strategies should be used during the research. Recording thoughts and practices in a research journal clarifies the researcher's understanding of their position in the research (Piantanida & Garman, 1999). The following vignettes are example of my journal entries:

> Research must begin from a person's concrete lived experience and include the experiences of marginalized group members in meaningful ways (Orbe, 1998). The person doing this research is the wife of an 11 year stroke survivor and is definitely positioned as an "outsider-within" in several ways. Most often, stroke research is done by health professionals, not by people with 'lay' experience. Additionally, I am not a stroke survivor. While I have an 'insider' perspective to stroke, as family of or caregiver to, this perception is still dominant to the voices of stroke survivors themselves. As such, I will need to be clear that I am hearing and collecting the participant's stories (Journal, January 12, 2009).

> After reading some of the thesis and dissertation reflections, I may not be the only outsider, it seems the young occupational therapists are feeling the same way. Maybe we all are flies on the wall (Journal, January 30, 2009).

Reflexivity in collecting data

Reflection was the researcher's route to participant responsiveness. Researcher responsiveness, the willingness to, "remain open, use sensitivity, creativity and insight, and be willing to relinquish any ideas that are poorly supported regardless of the excitement and the potential that they first appear to provide" (Morse & Richards, 2002, p. 11) is essential to credibility and trustworthiness in qualitative research. The Reflective Interview Analysis Guide (Roulston, deMarrais, & Lewis, 2003) was used to ensure the researcher was responsive to the participants and reduce researcher bias. This is an example of one answer in the eighth interview:

> He didn't mirror my question back to me in his response—I think because my questions are clearer. The questions were mostly open ended (80%) and he answered fully. He needed time. No overlapping conversation in this one. I asked some good probing questions that explained the issues further, a nice explanation of the search for recovery and wanting to work. I was able to use some good examples from the research this far and have him tell me whether that was his experience. Like Mr. D, policy is an issue. This really helped to confirm that it is the participant's experience. When he asked me about John, it added to the interview, because he then expanded on his health experience in Vancouver, and then here in Edmonton. It ties into Mrs. C's short rehab. I wonder why (Interview analysis I, page 1)?

In addition, when the researcher was not sure about the relevance of the data being collected to the study of activity, she stopped, reflected, and reviewed grounded theory methods.

Reflexivity in interpreting the data

The semi-structured interview questions (Appendix F) were developed around the ecological model. The questions guided the researcher to ask questions about how participant's activities were affected by physical environments, social environments, services, supports, and attitudes in the home, in the community, and at the policy level affected participants' activity choice. The researcher reflected on how this could bias interpretation. The researcher believed that Clarke's (2005) situational mapping, sensitizing questions, and recorded the open coding and analysis in Bell and Howell's (2008) conditional relationship guide helped to avoid gluing a theory onto a predetermined framework.

Reflexivity in drawing conclusions

At the end of the analysis, the researcher took time to think about the process, results, and how the participants would view the results of the study. This was a difficult process. The researcher was very reluctant to draw conclusions based on nine participants. The first conclusion submitted to the thesis supervisor demonstrated this problem. It was not a conclusion because the researcher was still struggling with how the research findings fit with health funding realities. Compared to the researcher's knowledge of stroke survivors and the published literature, these participants were atypically active. Morse and Richards (2002) recommend that researchers should seek bias, "deliberately choosing the worst case scenario or the best instance of an event" to move away from average experiences (p. 173). The researcher will take the study results to the peer reviewed publication process after further reflection about conclusions.

The researcher believes that her lived experience of stroke was beneficial in this research because the participants were treated sensitively, the knowledge contributed to richer interviews, and reflection resulted in a more rigorous research process. People with stroke and aphasia are considered a vulnerable population. All university students take ethics training and are aware of what vulnerable means ethically (ensuring that prescribed ethics guidelines are followed but also that the participants sensibilities are respected). But, the lived knowledge of stroke enabled this researcher to be aware of, and accommodate participant's needs (e.g., the researcher was aware of the time required for participants to frame responses).

The interviews contained rich data because of the interviewer's lived experience. Different interviewers, even using the same interview schedule, generate different responses from participants. Experience produces a more data (Rubin & Rubin, 2006). The researcher was able to use her knowledge of stroke to ask appropriate follow-up questions to help participants elucidate the issues they introduced.

The decision to use the Interview Analysis Guide (Roulston, deMarrais, & Lewis, 2003), Conditional Relationship Guide, and Reflexive Coding Matrix (Bell & Howell, 2008) was purposeful, to help the researcher reflect on the data and ensure understanding of the participants perspectives. After each interview, in the process of writing field notes and then in the interview analysis process the researcher specifically examined how the researcher’s experience might have influenced the process. The awareness and self reflection process contributed to more rigour in the research because the researcher was questioning why choices were made, the effects of those choices on the process, and recording those reflections in writing.

3.7 Summary

The theoretical framework, objectives of the research, elements of data collection, and process of data analysis used in this research were presented; the details of the strategies used to ensure rigour and trustworthiness in the study were provided. The process of moving from constructivist grounded theory (Charmaz, 2007) to situational analysis grounded theory (Clarke, 2005) was discussed. This exercise enabled the researcher to understand some of the differences between the different methodologies used by grounded theory practitioners, as well as to delineate the role of the social and physical environmental situations in participants’ selection of activities post-stroke.

CHAPTER 4

RESULTS

4.0 Introduction

This chapter presents the results of this study in three sections. First, Section 4.1 includes a description of the study participants and how they described the effects of stroke on their lifestyle. Sections 4.2 to 4.7 address the first research question: "What are the perceived barriers and facilitators associated with every choice of activities?" Last, Section 4.7 summarizes the results by answering the second research question: "Are there differences and/or similarities between two activities—one that stroke survivors have not yet resumed or had to give up and another activity they have continued?"

4.1 Description of the Participants

Three women and six men who were 1 to 6 years post-stroke were interviewed. They ranged in age from 53 to 64 (mean age, 58.2 years). Three women and three men were married and lived with their spouses. The other three men did not have spouses. Two men lived alone, and one man had teenage children living at home with him. Seven participants had left hemisphere strokes; three had right hemisphere strokes.

Severity of Stroke and Disability

Severity of stroke and level of impairment is most often related to stroke survivors' failure to resume personally meaningful activities (Clarke & Black, 2005; Rochette et al., 2007). Thus, it is critical to assess level of impairment of the study participants. The definition of stroke severity (i.e., mild, moderate, or severe) varies between studies (Gosman-Hedstrom et al., 2008; Rochette et al., 2007). Some authors consider severity at onset (Rochette et al., 2007), whereas other authors rate survivors' impairment at the time of the research (Duncan et al., 1997). For the purposes of this study, to classify severity, the participant's own description of how the stroke has affected them as well as time spent in rehabilitation has been used. These descriptions follow and are summarized in a table in Appendix I.

Mild strokes

Three people (Mr. E, Mr. G, and Mr. H) said their healthcare professionals classified their stroke as “mini” or “mild.” They have little visible physical disabilities, and their doctors did not suspend their driver’s licenses at the time of their stroke. Although they have no visible effects, all of these participants described residual problems. Mr. E said he is still troubled by aphasia; Mr. G has fatigue, mild aphasia, and some cognitive impairment he described as, “this is different, the brain, you can’t keep up with people” (Mr. G, p. 29). Mr. H said his physical health is excellent. In fact he rode to the interview on his bike, but says he cannot multi-task as he could before stroke.

Their doctors did not deem that stroke affected their driving ability. Mr. E was driving home from in-patient rehabilitation when a therapist asked why he was driving without undergoing a driving assessment.

> For the first two or three times I left [rehab hospital] I asked ah [wife], “Can I have the key?” She gave it to me, so I drove. And then ah, maybe the third day or fourth time I drove. I think it was my physio or speech therapist told me you’re not supposed to be driving (Chuckle). But we didn’t know … (p. 11).

Five hours after his stroke, Mr. G was discharged from the hospital emergency room and drove himself home.

Mr. E and Mr. H were both admitted to hospital and discharged home to wait for rehabilitation. Both spent 4 weeks in in-patient rehabilitation. Mr. G was not admitted to hospital or rehabilitation, but was assessed for rehabilitation 8 months after his stroke. He had returned to work immediately. Mr. H resumed work approximately 8 months after his stroke. Mr. E is on long-term disability.

Moderate stroke

Mrs. B and Mr. I had moderate strokes. They had longer hospitalizations, have less use of their affected arm and hand, and have mild aphasia. Both had their driver's licenses suspended at the time of the stroke, but they passed the post-stroke driving assessment some months later. Both said their right arms were not as functional, although Mr. I said his arm and hand were merely clumsy rather than unusable. Neither uses any assistive devices to aid walking, although both described a few residual problems with speech. They agreed that the speech and arm impairments are more noticeable to them than to the public. They are on long-term disability from work; however a family member casually employs Mr. I.

Moderate or severe stroke

Mrs. C's stroke could be categorized as either moderate or severe. At the time of stroke, she was unable to talk or use her right arm and leg. She received thrombolytic therapy (t-PA) to break up clots in the arteries that stopped blood flow to the brain, caused ischemia, and thus likely reduced the biological impairments. However, Mrs. C still has significant biological functional impairment. She has more difficulty walking and less use of her right arm and hand than Mrs. B or Mr. I. She walks with the aid of an ankle foot orthosis (AFO) to stabilize her ankle. Mrs. B did have her driver's license suspended; however, recently she was told by her doctor that she can take the driving assessment to determine if she can drive safely. Unlike the people classified as more severe, Mrs. C manages independently at home. Therefore, Mrs. C's stroke is classified as moderate.

Severe stroke

Three people (Mr. D, Mr. F, and Mrs. J) self categorized their strokes as severe. They all stressed that they were lucky to survive and credited rehabilitation, family, and community services for their regained abilities. All had left hemisphere strokes: two were hemorrhagic and one ischemic. They received 9 to 12 months of in-patient rehabilitation. Mr. D and Mr. F returned to their homes in wheelchairs. Mr. F was unable to walk. Mr. D said he was able to independently transfer from his wheelchair, and then walk a few steps with the assistance of a quad cane. Mrs. J was more mobile than the men. After 9 months of in-patient rehabilitation, she was able to walk up a few stairs into her bungalow and around the house. None of these participants had a driver's license, although Mr. D now drives a motorized scooter and Mr. F has driven a "quad" off-road, all-terrain vehicle at hunting camp.

All three participants rated themselves as being significantly more mobile now than when they returned home after rehabilitation. Mr. D says he walks 100 yards. Mr. F does not use a wheelchair at all, walks to the mailbox four times a day, and can climb up and down 14 steps. All continue to receive assistance from Alberta Health Services Homecare with personal care tasks like dressing and showering. Mr. F and Mrs. J receive additional assistance from their families whereas Mr. D lives alone, and must manage additional tasks himself.

The Shock of Stroke

Every participant was shocked when they had a stroke. They marveled at how little they knew about stroke before the event, as well as the steep learning curve that occurs after a stroke. The majority said their doctors had not talked about heart disease or stroke. Even Mr. E, a pharmacist, admitted he knew very little about stroke:

> "I didn't think about stroke. I didn't even know about the brain injury. To me a brain injury would be a concussion. You don't hear anybody telling you, 'I got stroke'. I rather hear about heart attacks or um what you call it quadruple by-pass or angioplasty" (Mr. E, page 18).

All participants perceived their risk of stroke was low. Participants believed that strokes happened to older people but not to people like them. Mrs. B commented, "I just found like I, it was not supposed to be me" and "I'm not like this... I'm not one of those, I'm not like those people, I'm not sick and that's it" (Mrs. B, page 14). When the researcher asked her to elaborate she added, "Handicapped, I guess, or you know and mostly they were like older."

That thread of the stigma of being disabled by stroke and of not wanting to be associated with "one of those" wove through each of the interviews. Participants distanced themselves by declaring they did not smoke, stressing they worked hard to recover, and hiding impairments. All but two participants (Mr. D and Mr. F) made it very clear that they did not have heart disease or stroke risk factors nor was their stroke caused by their lifestyle choices. Mr. E gave a typical response. He remarked that because he did not smoke, drink alcohol, and was not overweight, "even when my family physician knew [in hospital] about me, he came in and he was surprised." Most participants recognized that being disabled was stigmatizing and that other people treated them differently. Mr. I stressed that most people are to blame for their stroke.

> I think and maybe it's my own, my own prejudices and, that sort of thing, with respect to this thought…. But I sort of think that people that have strokes are generally smokers, or ah they eat too much greasy food, or you know, didn't live a healthy lifestyle or all of the above and maybe, maybe therefore, they don't get as much. Um, have people feel sorry for them and maybe, as much as they should. ….Why my kind of stroke, I had nothing to do with it, I had such a healthy lifestyle. When I was given all my um menus, and my eating habits at the Glenrose, they said, 'and you're perfect' (Mr. I, page, 22).

Several participants believed that they were assigned less credibility when they became disabled. The least disabled participants preferred to pass as non-disabled. They were careful to whom they disclosed they had a stroke, tucked their weak arm into a pocket, or avoided talking in social situations where effects of aphasia might be obvious.

> If ah you appear if you can take care of yourself then people normally will give more credence to opinion, just normal, (pause) but if you are unstable um, um illness or instability, whether it's family problems or whatever, um have a trouble then they're going to wonder about your ability to take care of your own self or family and therefore, whether your opinion is going to be tainted (Mr. D, page 6).

Pre- Stroke Activities

Prior to stroke, these 52- to 64-year-old baby boomers had been exceptionally involved, highly self-sufficient, and extremely engaged in their everyday personal, family, and work activities. They participated in a wide variety of productive and leisure activities. Pre-stroke, all were employed. Five men owned their own businesses: a property management company, retail business, engineering consultant, fishing and hunting guide, and motel/leisure business. The four employees worked in senior administrative positions. Many described their employment situations as demanding positions that required excellent multitasking, communication, and people management skills.

All participants, except for one, said they were physically active before the stroke. Mrs. B and Mrs. C had been marathon runners; in fact, Mrs. C had just qualified for the Boston Marathon. “I loved running,” Mrs. B said. “I used it to sort out my problems.” Mrs. J was a swimmer and water-skier. The men referred to coaching soccer or hockey, playing hockey, or going to the gym. Only Mr. F said he was inactive and overweight. They all had control and choice; they decided what they were going to do, with whom, and when. Participants talked about choice rather wistfully.

> It used to be if you’re isolated it was by choice, because you could go out and meet people, new people. Whenever you wanted to. If and when you wanted to…..And now unless you’re lucky, and have, some kind of mobility. [long pause…] and even then, if you don’t have ah health issues, which ah, means you know good days, bad days. …..you’re limited in the (pause) type of people, well I don’t mean that, I mean, in the people that you meet who are probably going to be [long pause…] sick to. You know, places you’re going to be, meeting people you’re probably going to be sick too (Mr. D, page 27).

Unquestionably, every participant in this study stated that disability from stroke changed the activities they do and how they do them. The change from busy to inactive was personally shocking: “You go from, I mean from doing everything to just sitting there kind of you know, I’m not able to do anything” (Mrs. B, page 3).

4.2 Facilitators and Barriers to Activity Using an Ecological Model

This section presents the results from the first research question: “Based on an ecological model, what are the perceived barriers and facilitators associated with the everyday choice of activities for those who have had a stroke from 1 to 6 years ago?” When describing the research and the role of participants in it, the researcher told participants that two activities were of interest: one activity they had resumed and one that they had difficulty resuming. The researcher asked them to think about which two activities that they would like to discuss. In the interviews, participants quickly identified two activities, but talked about many more. As they talked, the barriers and facilitators to those activities fitted quite naturally into four levels of an ecological model: the microsystems, mesosystems, exosystems, and macrosystem levels.

4.3 Microsystem Level

The microsystem is the setting in which the individual lives. It includes the individual’s family, relationships with close friends, and home (Bronfenbrenner, 2005, p. 148). It also includes the interactions that individuals have with family and with their peers and friends.

Microsystem Facilitators to Activities

At this level of influence, participants credited two factors as facilitators to their activities: themselves (i.e., individual responsibility) and the support of family and friends. Most participants believed that their individual responsibility and individual characteristics were the main facilitators to resuming activity. Then, they recognized that family and friends did help them to access information, meet the criteria to access services and supports, assist them with adaptation, and provide practical support. The third facilitator was individual and family management and negotiation skills. Participants and their families used the same skills they had used in the past with their families and friends, in their employment, or in their communities to co-opt the support they required.

Individual responsibility as facilitator

Participants (Mrs. B, Mr. D, Mr. E, Mr. H, Mr. I., and Mrs. J) believed that taking individual responsibility and control was the key factor to achieving their current activity status. They preferred to do as much as they could for themselves and gave examples of where they negotiated for control. They believed their individual characteristics like persistence, hard work, determination, optimism, bullheadedness, and adaptability were critical attributes to getting access to activities and the practical help they required. All participants talked about how they created opportunities for themselves by taking charge of their situation. Participants compared themselves to others who they believed were more passive to demonstrate how their personal strategies were more effective at helping them to gain control and access. They related how being fearful to ask, timid, and reluctant to adapt were barriers to resuming activities.

> Ah yah, I would say, it's, it's harder, it's hard to do [with mild stroke], but it's something to me you have to manage. You, again you have to need personality, I mean if you're a little bit timid before the stroke is not going to help it at all, (chuckling). You got to really confront it head on and stuff like that. What I have done, [I have done] alone. No, but no probably not. I wouldn't have got to the level. Maybe I'm, I'm a little bit of ah, ah, bull headed that way, I mean I just plow through it, because I know I have to. I want to be better (Mr. H, page 22).

Mr. I reiterated many times in the interview how taking individual responsibility was the key to accomplishing activity. He cited numerous examples of situations in which he took charge (e.g., refusing to use a walker, asking to use the treadmill, or demanding to do more exercise than therapists assigned).

> I don’t let it be difficult. I, you know it’s hard. Um, but I just get around it somewhere else. Well, I again I, I’m not one to sit around and wait for thing, things to come to me. So, as soon as I got ah, out of Glenrose, I got out on Friday and Monday I joined the, the um Millennium Place, the fitness centre, and I would take the bus down there every day (Mr. I, page 11).

The participants with severe stroke also believed that if they were optimistic, persevered, and worked hard, they would recover more than if they were meek and accepted their current position. This certainly was effective for Mr. F:

> I came home in a wheelchair and I couldn’t get out of a chair without a transfer belt. I don’t recall the last time I was even in a wheelchair, I used to go to restaurants always in a wheelchair but I always walk in now, and I walk most places. Yesterday [wife] went shopping at IGA and I went walking with her. So I do a lot of walking (Mr. F, page 9).

Supportive family and friends as facilitators

Also at the microsystems level, friends and family facilitated participants' access to activities, positioned them as capable, and included them in normal or regular activities. First, families and friends created opportunities for activities by seeking information, gaining entry in inaccessible situations, adapting activities to disability, and providing practical help. Especially when participants first had the stroke, either they weren't familiar with healthcare system access or rules or their disability made it impossible for them to advocate or get information for themselves. Family or friends were critical resources for information and to gaining access. Mrs. B revealed how a friend raised her priority in the hospital emergency department. Her friend, a doctor, had the power to access care. This vignette also illustrates the participant's ability to access resources.

> So I said, "Phone [friend] and tell her they're taking me to the U and so then actually Dr. [friend's husband] met us there, but I was out in waiting for emerg for quite awhile…. Maybe an hour. He [friend's husband] got it going, so they sent me for… I think it was a scan (Mrs. B, page 11).

Without significant help from family and friends, participants could not have reached some or all of their activity goals. Mr. F's story is an example of this need for assistance. He spoke about doing all kinds of activities, riding a recumbent bike, going to hunting and fishing camp, driving a 'quad' off-road vehicle, going to restaurants, attending a community stroke group, swimming for the first time, and reading 66 books. In each activity, an integral part of the process was family help to: negotiate access, support to adapt old activities or try new ones, and practical help with some tasks. Initially, when he returned home, he was confined to a wheelchair and required two people to transfer him from the wheelchair. His family believed that he should be included and that it was possible to adapt to activities to his disabilities. His oldest daughter and son-in-law created the access; they purchased the bike. His wife and youngest daughter found ways to help him adapt and provided practical help like transferring him onto the bike.

> Mr. F: All I could do……was a half a kilometer I thought well, I'm getting good. I worked up to riding it 27 kilometers a day and then I had two seizures so they cut me back , and now I do 20, I went down to 17, but now I'm back up to 21, I think. (Mr. F, page 16)

The second mode by which friends and families facilitated activities was by positioning the person as capable. All participants spoke about how disability made them different than they were pre-stroke. Then, interactions with family, friends, and professionals either reinforced their identity and abilities, or depersonalized them and positioned them as incapable. Participants provided examples of medical personnel ignoring them, community centre staff who would not accommodate them, and waiters in restaurants who disregarded them. Participants said it was friends and more often family, who defended their rights to be involved in making choices and decisions. Mrs. J recalled how the medical staff became impersonal after her stroke. "And you get treated like an idiot once you had a stroke. You're ignored as a person, by the medical people, I mean you get medical care, but they don't talk to [you] like you know anything" (Mrs. J, page 3). She believed that her husband's advocacy was critical in her medical treatment and ultimately her return home.

The third manner in which family and friends facilitated activity was by including the participants in ordinary situations as they normally had prior to the stroke. Inclusion indicated to participants that they still had a valued social position. It reinforced their sense of "normal." Mrs. B credited her friends for including her in ways that normalized her disability: "Ah, they don't treat me any different, I have to say, sometimes I have to say to them it's my turn, (laughing), and they stop and listen, you know" (Mrs. B, page 17). Her friends positioned her as the person she always had been, rather than as disabled and different. She made a direct link between how people treated her in social interactions to her participation in activities. When she was first discharged home she said she did not go out to the mall to shop because being disabled made her feel more vulnerable to physical assault or theft: "I could be a victim very easily because I can see me walking with a cane and I have a fight, I can't really defend myself"

(Mrs. B, page 16). Later in the interview, she talked about how her friends just took her to the activities they had done together pre-stroke, “And I, I like I said, my good friends, once I got out and like they, they never said you can’t do something. You know, they said okay let’s do that” (Mrs. B, page 26).

Skills of participants and their families

The third major facilitator at the microsystems level was the families and participants’ skills. They made resuming activity “their work” and they used their interpersonal skills to advocate for opportunities to participate, the resources they required, and the help needed to accomplish activities. Despite being in very negative positions at times, they still negotiated with therapists, their friends, and institutions. They solved problems, set goals, and successfully co-opted other people and institutions into complying with them. Mr. D smiled as he took credit for using his negotiating skills: “No they don’t always listen, so I have to swallow my pride, you know it’s like I don’t always get what I want anymore” (Mr. D, page 14).

In sum, participants credited their own ability to take charge of their situation, family and friends because they eased access, opened up possibilities of participating in new activities or old activities in different ways, affirmed to participants that they were still worthwhile people with a consequential meaningful position in their environment, and helped participants to integrate disability into their chosen activities. A consequential position was related to doing something that meant something to someone. The participants with the most disabilities received credit for doing any activity, but participants with few disabilities were only acknowledged with positive feedback for being close to their pre-stroke capacity. The third factor was the participants and their families’ skills and ability to find and utilize resources. Together, these factors increased participants’ confidence and bolstered their facility to take on activities.

Microsystem Barriers to Activity

There is a dilemmatic nature to facilitators and barriers. The same factors could be barriers to activity in one context and facilitators in another. While the majority of participants credited individual responsibility and families for helping them to resume activities, these same factors were barriers for a few participants. Individual responsibility became a barrier when families and healthcare providers put the onus onto participants to take charge of their situation when they did not have the skills or the confidence to handle the responsibility. Families became barriers to activities when they were unconcerned or overprotective. Related to being unprepared, the third major barrier was participants' lack of knowledge.

Individual responsibility

Some participants were not prepared for the amount of responsibility they were expected to assume. The survivors with fewer physical disabilities felt they did not receive rehabilitation or were discharged from rehabilitation services before they were ready for the independence. They felt abandoned and were unsure about how to proceed. All participants talked about cognitive confusion that made them unable to figure out how to complete tasks like making a phone call or going shopping. People with a severe stroke received help; those with small or moderate strokes were left to cope on their own. Mrs. C related this disparity in treatment directly to why she failed to resume running. She had been making progress, but as she increased her walking pace and distance, the tone in her foot increased.

> I think, ah I think I was walking okay and then I was walking on this side of my foot and nobody noticed it and it got sore so I stopped walking. And so I can walk but if I walk for a long time then it hurts on the side. So I don't know .... So I don't have any therapy right now. I think they think I should be able to figure it out on my own (Mrs. C, page 4).

One participant said her family believed she was not working hard enough. Several participants thought that other people perceived them as lazy because they were on long-term disability or fatigued when they did not seem disabled. A discourse associated with disability is that if people just worked harder they would not be as disabled or that people with disabilities are malingerers. The corollary of taking responsibility and pulling yourself up by your bootstraps is that if you are not reaching your activity goals or not recovering from stroke, then you have not exerted enough effort. Mr. E attributed these beliefs to his former colleagues because physically he has no visible effects of stroke.

> Yes, because it's business. And if, if you're sitting down with them…… they're thinking, that your trying [to] take advantage of them,…But if I don't, they're wondering what is he here for…..You know or, um if he's not getting involved with it, he's just……sit back……and just enjoying that free beer. Or… somebody is paying for, oh for your lunch, or……or if you're here, just maybe I have to pay the, the whole six for that (Mr. E, page 57).

Overprotection and disinterest

Either overprotective or disinterested family or friends were the second micro-level barrier to activity. Overprotection reduced participants' opportunities to engage in activities. Both prevented survivors from learning what they could do; they lost chances to practice skills functionally. It publically reinforced their incapability and increased their uncertainty in their abilities. Over half of the participants gave examples of people who did activities for them rather than letting them do them themselves. Mrs. J said her husband will not let her resume swimming: "I can't water ski, I don't swim anymore. You're [to husband] afraid I'm going to drown..." (Mrs. J, page 12).

His reaction was in direct contrast to Mr. F's families, who encourage and support him to try new activities.

> I'm so, so much different than when I came home [From hospital]. [Wife's name] took me in the ocean with this life……this little round preserver. And I did something there…that I never done, ever in my life. I can't swim and I never, ever been in the water with a life preserver, and my son-in-law, he said, "Okay jump in." They put the jacket on; no way I'm jumping in. Any way he helped me down these stairs, I was floating around, I could actually feel the bottom of the ocean, cause she was there …she convinced me it would be safe, okay (Mr. F, page 48).

A third of participants said their families hindered their recovery from stroke and their ability to participate because their family provided little or no support. Dysfunctional or disinterested families did not offer the help survivors required to carry out activities. Participants said that at times they needed simple help, like assistance to decide steps to solving a problem or to make a phone call. Some families were either not interested or did not recognize how much help and support survivors required. Mr. G believes he was not assessed for rehabilitation for months after his stroke because his family did not realize that he had aphasia and did not have the confidence to make phone calls.

> So I was, what I call all that almost zombie when this happened and, and not sure who's doing what ah, can't figure out the bureaucracy and um, a nurse on the research clinic, I had said to her, that I'm so tired, and you know is any of that, the way it is, and she said, "Oh, no it'll only last about 6 months". So I thought okay [....].
>
> I think it's a real big blow to my self esteem. Um, which is whole connected to their recovery? Um, can't get answers and you don't know who to turn to, and ah can't get phone calls returned and… so you just you get frustrated (Mr. G, pages 7-12).

One participant had to have police evict his son and his friends from his home. Not only did he not receive the required help from his son but dealing with the family dysfunction actually added stress during his recovery.

Lack of knowledge

The last barrier at the microsystems level was lack of knowledge and difficulty navigating through the systems. To be able to organize their time and their lives, people need to know where the right services and supports were located. Participants said they had a steep learning curve. Knowledge was often acquired anecdotally from other people or therapists in programs. If not admitted to rehabilitation or once discharged from rehabilitation, they had few opportunities to learn about available services and support. Reading material was not as helpful as it might have been pre-stroke for the following reasons: (1) participants could not read or had difficulty reading the material, and (2) if they could read it, they were not sure how to translate the information into knowledge that was useful for them. Even very able participants (Mr. E and Mr. G) said they had difficulty understanding written material. Participants wanted information they could use to solve their specific problems, but provided in such a manner that it was useful. This comment demonstrated one participant's frustration.

> Absolutely, and I, I've lost some brain cells but, I'm looking back and I was twenty-five years in Human Resources. I worked for the government and I mean we had more, I had to find stuff, it was, it was a piece of cake to find stuff, there's no, no challenge at all, and here I can't (Mr. G, page 27).

To summarize, microsystem barriers reduced participants' opportunities to engage in activities. If family and friends restricted survivors' activities by doing activities for them or preventing them from participating, they were not able to do the desired activity or gain confidence and self esteem from accomplishment of the activity. Equally as detrimental to activity was when the onus was completely on the individual to plan and carry out participation. Exclusion by family and friends reduced survivors' chances of getting support to carry out parts of the activities that they were unable to do.

4.4 Mesosystem Level

The mesosystem is a combination of two or more microsystem settings, essentially a system of microsystems. It comprises the links and processes taking place between two or more systems and settings (Bronfenbrenner, 2005, p. 148). At this level, participants had contact with three main systems: the healthcare system, the community system, and private businesses.

Mesosystem Activity Facilitators

Participants believed they had more control and influence at the micro-level with their family and friends because they were familiar with the people and the setting. Most participants did not know how organizations operated at the mesosystems level. At this level, the facilitators were level of disability, links between and to institutions, stable community programs, independent funding, and activities related to participant goals.

Level of disability as a facilitator

Individual disability ruled participants in and out of services. More severe stroke and visible impairments entitled people to services within the healthcare system, but excluded participants from community services. Conversely, being independently able to do activities of daily living enabled less disabled participants to use community facilities, but less disability reduced access to other supports. For example, the most disabled participants had access to Skills for Community Living supports but less disabled were not offered this service. It was difficult for participants to know what criteria were in place, in what institution, and in what situation. They often learned by trial and error what disability level qualified in a particular setting. All of the most severely disabled participants (Mr. D, Mr. F, and Mrs. J) had access to community care, case managers, and community agencies that provided services to people with severe brain injuries or physical disabilities. Access to these services provided participants with practical help, but also information and helped them to develop skills to access a wider range of activities. For example Mrs. J. has access to the Steadward Centre exercise facility because she is severely disabled. Regular community centers will not help her on and off machines but the Steadward Centre provides this service, “They just don't want you ...to use the standard rec centre. [….] They didn't have the staff, the argument […] why they couldn’t have me, it wasn’t safe” (Mrs. J, page 15).

Links between institutions as a facilitator

When institutions and agencies worked with one another, the opportunities for participants to choose activities increased. Participants felt the supports were more appropriate to their needs. Connections between the rehabilitation hospital, community agencies, and the clients provided participants with formal and informal information and help with specific problems. Rehabilitation hospital social workers, recreation therapists, and occupational therapists were excellent connectors for participants. For the most disabled participants, The Skills for Community Living (SCLS) program was particularly helpful. The workers introduced them to activities, referred them to appropriate services, and helped them to cope with changes in institutions and systems. Both Mr. D and Mr. F unequivocally stated that they would not have scaffolded from doing few activities to participation in regular activities without help from SCLS workers.

> Mr. D: They've provided me with ah sort of with a sort of a social worker, they saw me once every week or two. (Pause). Helped me with outings.
>
> Interviewer: Why did you need help with outings?
>
> Mr. D: Because of for distances further than 100 yards I was in a wheelchair that is why I got my scooter.
>
> Interviewer: So you were trying to maneuver manual wheelchair with….
>
> Mr. D: One good leg (pause) and one arm. (Pause…..)
>
> Mr. D: Just being able to go out, the first ah… year or so um, as I recall and I've been trying to put into words ah the hardest part was …ah, adapting to change. Um being in a fog, being afraid of change, (pause) I wasn't prepared to go out because I, myself, wasn't, um (pause…) prepared to um adapt very quickly. So it's not ah other people's opinions I was worried about, it was my own ability to ah cope (Mr. D, page 10).

Independent funding

Participants who purchased services or received funding from community care for independent funding to buy their own homecare services experienced a greater sense of autonomy and control. They could decide which activities they required help with and what could be assigned to the person they hired. Participants felt more comfortable asking for the supports they required because they were paying for the service. The reciprocity in the relationship seemed to create a more equitable power balance. Mrs. C and Mr. E both discussed how independent funding increased their options and control. Mrs. C was able to get help to put her foot into the cycles at a private fitness facility, but not at a municipal fitness facility. The vignette below illustrates the balanced power.

> Mr. E: But more importantly with going to the gym, I had a trainer.[lines left out for brevity, Mr. E speaks about types of exercises]

> Mr. E: So, okay I got first, two, three, I missed this [exercise], what's this reverse crunch, and front crunch was doing this way, so if I do it reverse it's backwards, right.
>
> Interviewer: Ah um.
>
> Mr. E: No, it's a different; it's a different way to do it. Or, ah so things like that, I [don't understand], I pass on that, and then I tell my eh my trainer that you have to show me how do I do this again. And he shows me again.
>
> Interviewer: So helpful?
>
> Mr. E: Yes he is. And he has to realize that, otherwise if he isn't, I won't be with him.
>
> Interviewer: Right… you're hiring him.
>
> Mr. E: Right and he's helping me (Mr. E, page 46).

Mr. F experiences this same control from the healthcare system with Community Care Independent Funding. He receives funding from provincial healthcare to hire his own homecare workers. Mr. F and his family decide who is best suited to the job, which tasks are done, and what hours are worked. The nurse they hired helps Mr. F to engage in regular activities like reading a book and walking to get the mail rather than doing the activities for him (e.g., reading the newspaper to him or getting the mail).

Stable community services

Stroke is a chronic condition. Survivors may recover ability, but the majority of survivors need ongoing supports. Participants benefitted from continuous community services geared to their needs. Stable programs enabled participants to develop friendships, establish secure social networks, and work on their goals. Participants described the benefits as being similar to regular community exercise programs for people without disabilities; participants became healthier, more mobile, and acquired more information. Social participation assisted participants to adapt to disability. Participants rated the exercise programs at the Steadward Centre and Fun and Fitness program as superior programs "very forward thinking" (Mrs. J, page 15).

Similarly, the two participants receiving support from SCLS workers believed the ongoing, regular support developed their skills to go out to community activities. This reduced their isolation and enabled them to continue to improve functionally and cognitively.

Activities related to participant goals

While physical and functional recoveries were important, how function translated into personal goals and meaningful activity seemed more important to participants. Participants preferred institutional supports that directly related to their goals. They felt like they had more influence if their objectives were the focus of the intervention. Focusing on their objectives developed their skills. They could relate supports directly to the outcomes they achieved. Participants' goals included return to work or to high-level leisure activities like golf and running. Without support directed specifically to returning to work, Mr. H believes he would not be employable.

> I'm angry cause I can't do some things, ah you know those, so you got to realize um, that you had a stroke. So you've got to ah sense that, step back and say, um 'yes that's probably happening to me'. 'What am I going to do about it? That's how I kind of approached it and [psychologist] helps me that, way' (Mr. H, page 10).

To summarize, services and support provided by mesosystems level institutions provided opportunities for participants to relearn skills and adapt to disability. All participants needed practical help. Participants valued the specialized knowledge that healthcare and community services provided. Work on participant goals or independent funding increased participants' autonomy. It gave them personal choice and control of their activities. People with more impairment had more access to healthcare services and those with less impairment had more right of entry in the community.

Mesosystem Barriers to Activity

Similar to the microsystem level several barriers mirror the facilitators, including the following: level of disability, gaps between institutions, and short-term community programs. Two additional themes were described as significant barriers by participants with less disability: services targeted to achieve minimal functioning and supports geared to institutional rules.

Level of disability as a barrier

Participants with less severe strokes were likely to find themselves excluded from health services or find services were limited. Community exercise and recreation facilities were not prepared to deal with very disabled participants. Staff did not have the time or training to provide participants with help to use equipment or adapt programs to their needs. Conversely, the Steadward Exercise Centre, specifically designed for disabled participants, excluded people with moderate biological impairment because they were too able bodied. Mrs. C requires significant practical help to fix her foot to bike pedals when she exercises. She is not disabled enough to qualify for the Steadward Centre; moreover, regular community center staff will not assist her.

People with less impairment were less likely to be admitted to a multidisciplinary acute stroke unit and experienced longer wait times for rehabilitation. For example, Mrs. B and Mr. H were admitted to overflow wards and Mr. E to a mixed medical ward. Wait times for rehabilitation were as follows: Mrs. C, two months; Mr. E, a month and a half; Mr. I, two months; and Mr. G, eight months. Access to stroke units and early rehabilitation is critical to regaining function. Given the same amount of rehabilitation, those receiving delayed rehabilitation never reach the same level of function as those receiving prompt rehabilitation (Biernaskie, Chernenko, & Corbett, 2004; Hicks et al., 2007). One participant (with mild stroke) did not receive rehabilitation. He believes his activity levels have been severely affected by the stroke, but also by lack of support. Although he has returned to work, he says fatigue and confusion prevent him from doing little else but work.

> A lot, absolutely, cause maybe this isn’t a big of a deal, but sure feels like a big deal. I don’t feel right, but you got the experts saying, “Well know, fatigue is going to end in six months,” and I’m getting more tired, so I started to think you’re going half crazy [….]

> I haven’t resumed much cause I think my biggest issue is the fatigue. I get so tired, um and the last couple of weeks I went to bed, like at, I’m in bed by eight-thirty, bed at nine-thirty [….].
>
> So, I didn’t get support through the health system and I sure didn’t get support at work (Mr. G, page 15).

Services and supports targeted at minimal function

Many of the participants complained that healthcare services and supports were not targeted to their higher-level goals and functions like return to work or complex activities. People with mild or moderate disabilities (Mrs. C, Mr. E, Mr. G, and Mr. I) wanted rehabilitation services and supports that would help them return to work or pursue leisure activities similar to pre-stroke levels, but over half of the participants (Mrs. C, Mr. D, Mr. E, Mr. G, and Mr. I) believed that people were discharged as soon as they were able to perform very basic tasks. They believed that healthcare services targeted to achieve basic activities prevented them from returning to work or to more meaningful leisure activities. As the following quote demonstrates, these participants did not believe services were adapted to their rehabilitation requirements.

> Get me out the door. Their just, they, they, have it in their heads that they keep nobody longer than three weeks. [….] Well in fact, (sigh) I was interviewed by the um, ah speech therapist and by a couple of speech therapist, and they said, ‘We feel that you have enough coping skills and, and ah you are aware enough for yourself. That you know we’re not going to be able do anything for you that you can’t do for yourself’ (Mr. I, page 15).

Gaps in institutional links/ referrals are a barrier

Gaps in services made it difficult for participants to access the support they needed to participate as fully as they expected. Participants found healthcare and community systems confusing. They were not sure what services they needed, or to what supports they were entitled. Even if they knew what they needed, they were not sure how to proceed or could not find a suitable entry point in healthcare or community systems. Participants were particularly unclear about which community agency was responsible for providing what services. Some participants were referred to community agencies (Mr. D, Mr. E, Mr. F, and Mrs. J) whereas others who might have benefitted were not (Mrs. C, Mr. G).

> We don't know anything…I don't know I, I, I know of a heart attack, I know nothing about stroke, never think I would have a stroke. Well after discharge of the Royal Alex Hospital we were told to go home and wait for a call to get into the rehab program. And again not knowing anything we just listened and sat home and waited, and waited, and we still got no phone calls …. So any I think I drove 3 times….. we just don't know (Mr. E, page 12).

Participants not linked into the rehabilitation system were particularly frustrated by the complicated referral patterns. Specialist staff at the rehabilitation hospital had the greatest knowledge of the available services, but this support was not offered to non-patients. They were expected to get information and support from their primary care physicians. Both Mr. F (longest hospitalization) and Mr. G (never admitted to hospital) said family doctors were helpful with routine medical problems like monitoring blood pressure or checking cholesterol, but did not know what to do about impairments like spasticity, splints, fatigue, or aphasia. Mr. I complained that his stroke was caused by gaps between services. In hindsight, he says he should have known more about his anticoagulant medication.

> Mr. I: [Heart surgeon] so he came over and said, "[Mr. I] how are you doing." He remembered my name and he said "I can remember what your heart looks like, you know." He remembered he had taken only half the lining out and he couldn't [take all] cause he was damaging the heart too much. So he left the half back end, and then he said, 'What happened? How come you had the stroke?' And I said, 'Well, I was having too much Coumadin.'
>
> In fact, your, your INR reading should be between 2.5 and 3, when you're, when you're taking that Coumadin and ah, ah I, I checked mine every month, regularly and I have gone in on the first of every month and I've gone the first of November, I recall and um, it was fine, it was reading was three. And, at Vancouver when I went in the hospital [with stroke], they checked it, checked my blood level, INR my blood and it was 9.3. He said, 'Coumadin! What are you still doing on Coumadin? You should have been off that long time ago' (Mr. I, page 6).

Short-term programs/ cancelled programs are barriers to activity

Stroke is a chronic condition with ongoing long-term disability, but the programs were short term. Participants complained that early discharge dates, mini education sessions, and cancelled programs limited their ability to adapt socially and recover physically. They were dissatisfied with community programs, who they thought were staffed by volunteers with similar knowledge to theirs (Mr. G, Mr. H, Mr. I, and Mrs. J). They felt that many of the programs offered by healthcare and community agencies were “little programs” designed to keep them busy for a short time, not to motivate them or help to achieve their goals.

> ...they’re not particularly interested getting better, and pretty minimal cheap and some of them have good reasons to be down there, and they haven't had all the advantages we had, none (Mrs. J, page 6).

Short-term programs or one-size-fits-all programming did not provide these participants with the specific information or knowledge they required to help them manage complex health problems, nor did they increase their activity levels. The following participant was the most vocal about generic programming. It addressed smoking, diet, and exercise, but not his concerns.

> Yes, with some um, I don’t know what, what’s appropriate to do that’s part of my frustration, I’m not sure if it’s and ah um an activity that ah hasn’t resumed because I’m real tired, but I want to go to bed early and do the right stuff, but I want to exercise, you know. But I don’t want to exercise too much cause then I get the chest pain, but so I went to… Risk Reduction series as I have mentioned and some of it was on Monday, you know how that works, eh […] there’s five sessions as you know, the smoking I didn’t have to worry about, but ah it just took a while (Mr. G, page 11).

Participants’ program landscape kept changing. People were discharged from programs or programs were cancelled. Mr. D believed that it was the responsibility of the healthcare system to provide funding for ongoing stable exercise and social support programs.

> I think it’s good that they raise the tax on things that make people ill. But um, they should equally spend the money that they get as a result on ah, (pause) on an aging population on, on maintaining their health, not just treating their illnesses. (Pause…) it’s just an opinion (page 19).

> It’s only 45 dollars a month for two days a week, because they have like 90 people, seniors mostly, ah serious handicapped using it. But what the government doesn’t realize is they’re going to find out is that lot of those 90 that are going to become patients in the hospital once they close down the program, so they’re going to get what they wish for. (Laugh) They’re going to have those 90 patients admitted. Though ah and they’ll really spend a lot of money on them, because they’ll be patients and patients take a lot more money than mobile day patients (Mr. D, page 20).

Activities related to institutional rules

Participants (Mrs. C, Mr. D, Mr. F, Mr. G, Mr. I, and Mrs. J) complained hospitals were more worried about their rules than patient activity goals. They felt that therapists had to choose between following their goals or the institutional rules like ensuring they prevented falls. Participants believed this limited their rehabilitation and reduced their activity potential. Participants did negotiate for their autonomy as the following quote illustrates.

> I’d weaned myself off wheelchair, they, they really fought me for that, and I, I just said, “I’m not going to be bound to that wheelchair,” and ah they tried to give me a good old walker and I said, “No,” so then they finally agreed on a cane.
>
> Well, otherwise, (sigh) I was very disappointed in their physical therapy. Um, they first of all they didn’t want let, let me use a treadmill, (chuckle) because no one could, would be there to ah, to supervise me. No. Um, and they’re more interested in covering their butts, than making me better. You know, (sigh) they didn’t want to let me use any of the equipment, unless they were there, and I said, ‘What are we here for?’ [They said], ‘What if you fall?’ ‘Oh’, I said, ‘If I fall, I’ll get up’ (Mr. I, page 16).

To summarize the mesosystem activity barriers, people with significant biological impairments were able to access a wide range of healthcare services, but some were excluded from community services. Most (but not all) participants with mild or moderate stroke found their healthcare support was limited by institutional practices and policies that placed emphasis on achieving activities of daily living. They were left to achieve high-level goals like returning to work or running on their own. Participants wanted to resume pre-stroke productive work or leisure activities. All participants had some difficulty navigating unfamiliar and disparate community and healthcare systems. Not knowing what the institutional rules were or how the institutions operated increased participants' uncertainty about what support and service options were available, appropriateness, and how to access them -- ultimately decreasing their opportunities to work at their own higher-level activity goals.

4.5 Exosystem Level

The exosystem encompasses events and process that take place between two or more settings, but outside of the individual's immediate setting. The events influence the processes within the immediate setting that does contain that person (Bronfenbrenner, 2005, p. 148). Various levels of government fund healthcare, community programs, recreation centers, and transportation. Participants had little control over government policies and institutional regulations, but the effects of those policies influenced their access to activities.

Exosystem Facilitators to Activities

Municipal, provincial, and federal government policy ensured that all participants received excellent healthcare and had the financial resources to purchase food, clothing, and shelter. While participants believed that healthcare and social services should be more responsive to their needs, especially in a province as wealthy as Alberta, they were aware that the services they did receive were instrumental in the level of recovery they had achieved. Participants all believed that rehabilitation services and rehabilitation funding were critical elements in their recovery and in enabling them to participate in activities.

Exosystem Barriers to Activities

Government and institutional policies restricted participants' choices. Rules and restrictions in the healthcare system, social services system, and tax system influence access to services and supports. Participants had trouble understanding criteria and navigating through polices at different levels of government. They identified three major policy areas that hindered their participation: adaptive equipment policy, wage loss/employment policy, and environmental adaptations.

Adaptive equipment policy

Over half of the participants used some type of aid to assist mobility (e.g., ankle foot orthosis, Walk Aide, wheelchair, or scooter). Numerous restrictions existed regarding eligibility for adaptive aids and how out-of-pocket expenses for these aids were treated within the provincial healthcare system, the provincial social service system, the federal tax system, and by their private insurance. It was difficult for people to know their eligibility under the various systems, approval procedures, and payment arrangements. Negotiating between different policies and among different levels of government was difficult for the majority of participants. They found it worrisome and time consuming; the delays obstructed their adaptation to disabilities. Mr. D explained how his decision to purchase a scooter conflicted with his income supports. In this case, he had to understand adaptive aids policy through the healthcare system, income support policy at the provincial level, disability tax credit policy, and retirement savings policy at the federal government level.

> I cashed in some of my small RRSP to buy my electric scooter, and the government said that was income so they cut me off AISH… I'm down to a dollar a month now, because I have an income, cause cashing in your RRSPs is considered an income. Ah, luckily um, my case manager ah... found me a financial advisor with ah, (pause) home care. Now I'm also on Alberta adult benefits so, she managed to get me on that just in time to ah, get my, dental covered. I got cleaning done last fall, and that covers my ambulance and my $150 a week pill habit. You can say I'm on three different nerve medicines and cholesterol pills and what not. And not to mention vitamins, but otherwise I'm living off my RRSP. And then last year I decided to cash in some more of my RRSP to pay off my credit card debt, it wasn't much, but it was 21% interest, so…. I'm waiting for the government to decide that was income too and ah, cut me off Alberta Adult Benefits.
>
> Well, it makes me mad, cause it's not income it's my savings. They're not making me use my savings but yah, in a way, I have to use my savings to, um, pay for the scooter so that I'm more mobile and or else, I'd ask them to pay for ah… electric wheelchair for me. So I'm saving them money. And yet they're penalizing me for it.

> They would [pay for an electric wheelchair], but… not a scooter, but the electric wheelchair wouldn't be as good as this [scooter] outside. It wouldn't be as stable. And… for what I've researched, it wouldn't have as good a range. It certainly wouldn't be able to carry any groceries on it (Mr. D, page 25).

Income supports and work policy

Participants wanted to work in either paid employment or volunteer work. The majority believed that work would help them regain the status lost when they had stroke. However, several (Mrs. C, Mr. D, Mr. E, Mr. I, and Mrs. J) found that disability income policies precluded employment. These policies do not take into account how difficult it is for participants to work with stroke disability. First participants found they encountered prejudice when they attempted to find employment.

> So, once your, once your health reputation is damaged, if somebody has known you before, it's very difficult to get that back. It's like going back to work at your old job, it's going to be hard to get back [to] your old job even if you can, you have to prove yourself (Mr. D, page 28).

Second, maintaining employment was difficult because they required more time to complete tasks with their stroke disabilities. Third, they earned less money than they would have pre-stroke. Fourth, they could not count on earning reliable incomes, because their health was fragile sometimes they were unable to work. They worried about losing their disability benefits, a stable source of income, if they volunteered or did earn some money. On one hand, income supports restricted how much they could earn when they were employed, but on the other, disability employment policy meant to protect disabled workers, was not a defense against discrimination and job loss.

> I was going crazy being unemployed and so I got a job here in Edmonton with a friend and ah, I had to give it up. You know, I wasn't that farther ahead, I didn't get more, earn more. I mean that's, that's like peeing against wind storm, but you know, you… It's such a big wall to fight (Mr. I, page 25).

> Well, (longer pause…) any income bearing, um securities, let alone ah working for an income. Um, I think you can earn a maximum of 400

> dollars a month right now, like that’s, that figure has increased to 400 dollars a month, if you’re on AISH, which is (beeping - telephone) it isn’t much, if you’re trying to look for a job, while you’re, severely handicapped, trying to pay bills. (Pause…) so your gain, again you’re, you’re kind of, handicapped and what you can do to support yourself, even if you’re well enough to work (Mr. D, page 26).

Summary of Exosystem Facilitators and Barriers

Long-term disability, income supports, and healthcare benefitted all participants. However, once participants got past basic services, they found that policies and supports from different institutions conflicted. Income supports, disability tax, and healthcare policies at different levels of government were not coordinated. Participants were confused by the silos between different programs, departments, institutions, ministries, and governments.

4.6 Macrosystem Level

The macrosystem consists of the cultures, subcultures, and broader social contexts overarching the micro, meso, macro, and exo systems (Bronfenbrenner, 2005, p. 150). Participants reflected the deeply held negative cultural beliefs about aging and disability held in Canadian society. Cultural belief systems constrain or create possibilities at all other systems levels by privileging some discourses over others.

Macrosystem Activity Facilitators

Participants’ comments reflected beliefs espoused in the Canadian Charter of Rights—equality, social justice, and human rights for all people including those with disabilities. They believed that services and supports should be available equitably. Participants (Mr. I, Mrs. J) who spoke about this believed that they had a right to accessible services.

Policy support for equity

Participants provided several examples of how disability policy enabled them to continue activities. They noted that airline and train travel were particularly accessible and that this was the result of advocacy and cultural change. Mrs. J compared her situation with her father’s, noting it was easier for her to travel. Mr. G pointed out how that accommodation for people with disabilities enabled their full participation in society, although he believed that accommodations were more readily available for his children than for him.

> I have four kids, two step daughters and two kids, ah that are mine. Um, that have, disability called learning disabilities. You get lots of accommodations and that's why they're succeeding. Yes and so I think there should be accommodation (Mr. G, page 16).

Macrosystem Activity Barriers

While participants recognized that disabled people should have a place in society, they still reflected the deeply held societal stigmas about age and disability. They spoke about how little they knew about disability before their stroke and why people with disabilities were treated differently. One participant referred to it as "losing your reputation" (Mr. D), but many people talked about how the public, former colleagues, and even family members ignored them. Their social networks disappeared in part because they were not able to participate at the same pace or level, but also because society is not prepared to adapt to their slower pace. They even reflected on how healthcare services might be rationed to people of different ages and varying levels of impairments.

Ageism and disability

Before their stroke, most participants said they believed stroke happened only to older people. Participants did not want to be positioned as older and disabled because it was not normal or valuable socially. As described earlier, participants with few disabilities tried to hide their impairments. They felt it made them vulnerable to attacks from others or downsizing at work.

> I think more older than anything, cause they don't know me if I smoked or don't smoke, whatever. So they usually say, 'Oh, that's usually older people.' Handicapped I guess or you know and mostly they were like older and after awhile mostly they were just older, you know just, I'm not sure to explain it. I just thought I don't want to be here" (Mrs. B, page 5, 13).

Mr. I connected limited rehabilitation for resuming paid employment directly to the beliefs that older people are "at the end of your wire" and not likely to be productive. Similarly, Mr. E discussed how limited funding in the healthcare system made it difficult to decide who should get rehabilitation services. He wondered on what criteria services should be based: age, motivation, disability, or capacity to recover.

> So, it, it's a choice, who do we give it to? Do we give it to one that it's easier to do the rehab or the therapy? Or do you help the ones that are worse, the tougher ones, and the ones that say, no I don't got a problem, nay, I……don't want to go. There's… so many choices, um… it's, it's a really tough ah question about that. For me, ah, I'm fortunate, because I'm strong, I'm too young. For me, still enjoying maybe 75% (Mr. E, page 49).

Summary of Barriers and Facilitators to Activities

Three themes threaded through the four systems levels: (1) access, (2) inclusion, and (3) practical support. In general more access and inclusion were catalysts to activity. However, like the barriers and facilitators at each level there was a dilemmatic nature to practical support. Too much or too little support practical help impeded participation. That quandary suggests there is a timing and dose effect for access, inclusion, and practical support.

At all levels the same factor could be a barrier or facilitator to activity. At the microsystems level, on one hand, individual responsibility was a facilitator to activity. People took charge of their new situation and worked to figure out how to resume activities. On the other hand, participants were expected to take control of their health and disability without the knowledge or skills to manage their health or navigate complex systems. Similarly, family and friends could provide practical help and support in the right amount and at the right time or they could provide too much or too little support. At the mesosystems level, the amount of impairment entitled some people to services and support in some situations, and excluded them in others. It was difficult for stroke survivors, family, and friends to know how to approach this new situation.

Access was a catalyst to activity. System navigation was difficult for all participants. They did not know how to access unfamiliar systems or to what services and support they were entitled. Participants got caught between different policies at different levels of government when they tried to purchase adaptive aids and return to work. Factors that facilitated access to participation were participant's persistence, helpful family and friends, referral systems between institutions, and guidance from people in those systems. Factors that obstructed access were being on your own, lack of information or skills to use information, lack of support from others, limits to services based on impairment level, silos between services, conflicting policies, and stigma of aging and disability.

Inclusion was the means by which participants regained confidence to try tasks and participate in activities. Inclusion was related to how participants were positioned socially. If they continued to be treated as competent individuals and included in their social context by family, friends, and/or people in healthcare and community systems, they were more likely to have access to opportunities to pursue activities and to co-opt practical support. The factor that supported inclusion was people's attitude to disability. Factors that obstructed inclusion were power imbalances between the participants and service providers and the stigma of disability and age.

The factors that made practical support accessible were similar to those that supported access and inclusion: participant's ability to seek and accept support, someone willing and available to help, and institutional/government funding and policies. Factors that impeded practical support were being on your own, people unwilling to help, and institutional and government policies restricting different types of support.

Whether a particular factor operated as facilitator and barrier to activity also depended on timing and dose. Participants wanted access to personally meaningful activities. Choice of activities would seem to be more important than the amount. More inclusion (at all times) was a catalyst to activity, but even more so when participants first arrived home. At that time, most said they were frightened and insecure. Practical support was more dose and time dependent. Too much or too little support hindered participation.

4.7 Similarities and Difference between Resumed Activities and Non-Resumed Activities

This section explores the findings associated with the second research question: “Are there differences and/or similarities in the two activities that participants had to give up and those activities they continued?” Participants talked about a number of activities beyond the one they had resumed and had yet to resume. First, a general overview of participants’ two selected activities is presented; second, the similarities between the activities are investigated; and third, the differences between resumed and non-resumed activities are examined.

Activities of Choice

The nine participants were asked to talk about two activities. Of the eighteen chosen activities, work was selected in seven instances. Two male participants discussed it as the activity they had resumed. Another male participant chose to discuss becoming a condo board member, which was very similar to his pre-stroke job helping volunteer condominium boards manage. Two participants (E & I) said they had resumed everything but work; these participants chose work as the activity they wanted to resume. The other 11 activities involved leisure. Participants had resumed golf, reading, fishing, and going to church and wanted to resume running, swimming, driving, and social relationships. Table 4.1 provides an overview of resumed and non-resumed activities.

Table 4.1 Comparison between Resumed and Non-Resumed Activities

Severity	Participant	Age	Sex	Activity Resumed	Activity Not Resumed	Access	Inclusion	Practical Help
Mild	E	59	M	Everything but work	Work	Short rehab time/ slow access to rehab	Family/wife Volunteers Professional Alumni Association	Wife phoned rehab/ organized volunteering
Mild	G	58	M	Work	Social activities	No rehab	Family unsupportive	Some help from family doctor/
Mild	H	59	M	Work	Relationships	Admitted to rehab	No family/ admitted to rehab (alone)	From rehabilitation psychologist
Moderate	B	53	F	Golf	Running	Recreation therapy	Friends	Friends and husband/ golf cart
Moderate	C	53	F	Reading	Running	Short rehab/ discharged	Family/ alone during the day/ work harder	Functions independently/ family
Moderate	I	64	M	Resumed everything slowly	Work	Policy/Services not designed for back to work	Wife is breadwinner	Functions independently/ wife
Severe	D	58	M	Condo board	Fun and Fitness	SCLS worker	Alone, Supports from system	Homecare, SCLS
Severe	F	61	M	Fishing	Driving	Family, SCLS, Rehab	Family, friends, SCLS	Independent funding / family/ friends/ SCLS
Severe	J	59	F	Going to church	Swimming	Family/ Community Care/ Steadward Centre	Family, close friends	Family, Community Care

Similarities between Resumed and Non-Resumed activities

The major similarities between resumed and non-resumed activities included: (1) pursuits that anyone 50 to 70 might enjoy, (2) performance was significantly affected by stroke, (3) activities participants enjoyed doing pre-stroke, and (4) all actions were works in progress.

Ordinary activities

The most striking similarity about the activities themselves was how ordinary they were. These were productive and leisure occupations that might interest anyone aged 50 to 70. In fact, sometimes as participants were talking about activities, it seemed the conversation would not have been out of place with a friend over coffee or at a cocktail party. Participants were relating problems to stroke, but they could just as easily have been attributed to healthcare system access, inclusion in the workplace, or lack of funding for support. For example, when Mrs. B tried to resume running, she had to stop because she tore the meniscus in her knee. The conversation centered on access to healthcare: how the diagnosis was different in different healthcare settings, the wait times for surgery, and amount of therapy available. These same issues are commonly discussed on the nightly television news. Similarly, Mr. G and Mr. H found that resuming social relationships and social activities has been difficult. They questioned how they handled social situations with girlfriend or work colleagues, what they said, and how, in this instance, it was misunderstood.

> I am still not emotionally, I'm questioning my judgment. Um, initially I, actually think what’s really affected is my wit, and I thought like, what I said isn't witty anymore. And it isn't ah, it's actually downright insulting, because I picked the wrong group of words, eh, and um, so I worked on that, to try to get that back to......where I was... (Mr. H, page 18).

Significantly impaired activity

In participants’ estimation, both resumed and non–resumed activities were significantly affected by stroke. While this observation may seem obvious in severe disability, it was surprising when participants seemingly with complete recovery described how fatigue, difficulty multi-tasking, or small errors in speech significantly affected their confidence, their relationships with other people, and how they approached activities. The majority of participants believed the onus was on them to adjust their behavior or performance, rather than anticipating that other people might adjust to their disability. The following vignette is a good example of how Mr. E worried about other people's perception of his minor disability. This participant's anxiety changed his social relationships and how he now approaches social situations.

> I said hi to my employees, one of ah part-time girls, a young girl, at that time she was in university. She just walk[ed] into the back of the store and I said, 'How are things going, why don't you sit down and… see how things are.' Instead of saying sit, I said the four letter word. What I told that lady....., fortunately it didn't last a lot longer, and [name] probably realized I made the wrong word. And, I apologized to her.
>
> But, if I… didn't accept it, and I knew [that I] made that mistake, and I just, I was hoping that she didn't hear that either. And if I don't tell her maybe she thinks I'm normal. Okay, so I won't tell her. But, what happens? She doesn't necessary have to tell you. But she does know? And she may think that he's taking advantage of me or he doesn't treat me.
>
> So, I usually have to double think before I say the word, because if I was [in] a restaurant and I want um dessert, I usually would say desert automatically. So what I do is I pause, a couple of seconds before I say that word (Mr. E, pages 31-35).

Personally meaningful: re-making an activity reputation

These activities were all important to participants before stroke, but attempting to pursue pre-stroke activities also gave them a useful position in society. Being able to return to these personally meaningful activities was a source of pride and a marker of progress towards returning to pre-stroke lifestyle for individuals themselves. Perhaps more importantly, activities were markers of social status. Participants believed that resuming or even trying to resume activities gave them social standing. Any return to activity was significant to all participants, but small gains were celebrated more by participants with severe stroke. It was the social meaning of activity that was important. Mr. D was very clear about how returning to the board of directors as a volunteer and working towards resuming regular fitness programs, reading, and writing were all tied to meaning in his life, a large part of which is his position in society.

> Not everybody sees you, going to see you, as a person with something to give they're going to look at one part of you and that's the damaged frail part, too frail maybe to have a relationship with. So it's very hard, it's like your reputation. Once your reputation is damaged you'll never get that back. So, once your health reputation is damaged, if somebody has known you before, it's very difficult to get that back. It's like going back to work at your old job, it's going to be hard to get back, your old job even if you can, you have to prove yourself.
>
> Well I [was] non-society and now I'm contributing to… society. I feel like um utilizing using um my expertise to, to some and contributing because for the first couple of years I wasn't feeling useful. Like most people I guess when they retire. You know when you retire and don't have a hobby or don't have something to do with your time, your self-worth is taken away from with your job, ah you get depressed very quickly. So when it's taking away just cut off like that it's a double whammy, especially when you don't have an income anymore, pension, or anything. So you lose your financial independence, and your mobility. So it's nice to be able to contribute again (Mr. D, page 27).

An activity continuum: works in progress

Both resumed and non-resumed activities were works in progress. Most (but not all) participants spoke in hopeful terms about non-resumed activities as their next step or something on which they were now working. Participants continued to perfect resumed activities to bring them closer to their pre-stroke level of performance. Activities (both resumed and non-resumed) were described in a series of steps. Mrs. B explained how she resumed golf: hitting the golf ball a few inches, then a few feet; had to ride a golf cart around the course, now walking the course; and initially not counting her strokes, then breaking 100.

Mr. F used the term scaffolding to describe the process of doing whatever activity was possible, gaining more complex activities, and working towards resuming pre-stroke activities or new ones.

> I could do maybe three or four [referring to lifting a weight with his affected arm], and then [wife] bought me one, so I do that. I scaffolded (Mr. F, page 46).

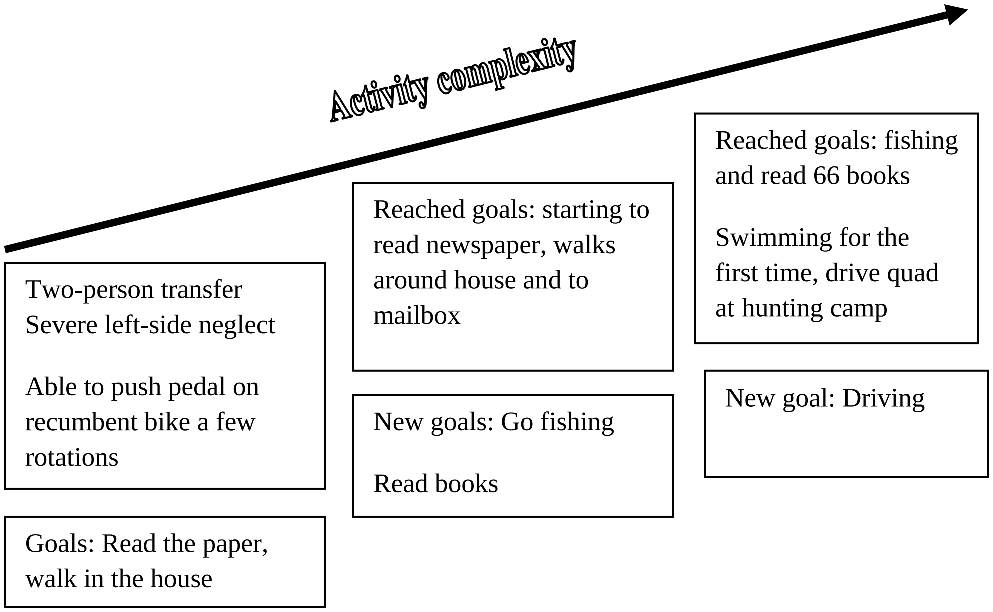
As possibly the most disabled participant in this study, Mr. F exemplified how scaffolding from foundational activities translated into more complex tacks, and then into activities that he enjoyed pre-stroke (or even things he had never tried). The process was the same for resumed and non-resumed activities and across the majority of participants.

They recognized they could not work on all activities, and had prioritized tasks and activities towards their major activity goal. For example, both Mr. E and Mr. I wanted to return to work, and both were using strategies to make that happen. Both continue to perfect their speech. Mr. H has returned to work. But, he said he still struggles with mild aphasia. He provided several examples of the steps to work, then how he adapted at work, and the remedial steps he continues at work. He uses the same tactic to work on relationships.

> And initially I couldn't even find [any words], I would just sit there like a dummy. So first, I want to get my conversation level [back] …and so I would tend to think, ya this doesn't sound like me or why am I doing these things? So I would really consciously think about what I was going to try to portray. You know just being in the work environmental think really helped me.
>
> I produce documents and I still have a problem with that. Um but I guess the advantage I have, I've been working in this business for 9 years and I've got a few tricks that I do (Mr. H, page 13).

The similarities in the process between resumed and non-resumed activities is illustrated in Figure 4.1.

Figure 4.1 Process of scaffolding to activities



Participants considered both resumed and non-resumed activities as realistic possibilities. The complexity of the selected activities was related to the level of the participant’s disability. Participants with greater disability wanted to resume less complex leisure activities like exercise classes or swimming; participants with moderate disability talked about running or resuming work. The two participants with mild stroke were working at higher-level activities.

As participants became more active and resumed activities through recovery, adaptation, or with practical support, they had higher activity expectations. Mr. F’s story exemplifies this process. He was unable to walk when he came home after 1 year of in-patient rehabilitation. He required two people and a transfer board to move from wheelchair to toilet or bed. He had severe left-side neglect. Now he walks to the mailbox twice a day, climbs up and down 18 stairs in his two-story home, and rides about 20 kilometres on a recumbent bike. His resumed activity is fishing, and his non-resumed activity is driving. He did not consider driving a possibility when he first came home, but as he worked at re-learning to read, he also started to be aware of his left side. Recently he has driven an off-road recreation vehicle at the hunting camp.

In sum, the activities chosen by participants were usual activities for people of their age. Resuming or attempting to resume activity was meaningful to participants in part because it gave them social status. It may seem simple, but the process of resuming activities was the same regardless of disability level or activity; participants scaffolded small tasks into meaningful activities.

Activity Differences

Unquestionably, all participants said impairments from stroke were a problem in resuming activities. In this study, it must be noted that when participants chose non-resumed activities it seems that they have selected activities that they thought they should be able to resume with their level of disability. Participants indicated that they received less support to participate in non-resumed activities. For example, Mrs. B had been running and would have resumed running after her knee surgery if she could be sure that she wouldn't tear her meniscus again. Mr. D had been attending group exercise classes until they were cancelled. Mr. I had gone back to work, but his earnings were less than on his disability pension. In resumed activities participants had: (1) more opportunities to participate, (2) accepting social environments, and (3) practical help to assist them when cognitive and physical impairments prevented them from engaging in activity independently.

Access

Access was a critical first step for all resumed activities. In resumed activities, participants had opportunities to pursue the activity. Participants' opportunities to do activities were facilitated at all levels of the ecological model. In resumed activities, someone helped participants to navigate the various systems levels. Family advocated for rehabilitation, searched for doable activities, found accessible facilities, and provided transportation. Friends were sources of information. They could help participants to meet criteria for entry to institutions. A friend who worked at Revenue Canada helped Mrs. J fill out the Canada

Pension Plan disability forms so her claim was not delayed in the system. Her private disability insurance was delayed because the form she tried to fill out herself was incomplete. At the mesosystems level, participants who resumed more activities had more access to healthcare and community supports. They were admitted to rehabilitation, and through that had access to recreation therapy, community care, and the Skills for Community Living Workers. For example, Mrs. B says it is unlikely that she would have played golf without access to help from the recreation therapists.

Participants had less access in non-resumed activities. Sometimes families blocked activity; other times the family did not provide required help or the participant did not meet the institutional entry criteria. As described earlier, Mr. F has learned to swim because his family gave him access. However, Mrs. J’s husband feels it is too risky. In the cases of participants with mild stroke, all three male participants were discharged home from acute care hospitals to wait for rehabilitation. Mr. E believes his family facilitated access because his wife called the hospital daily for a month. Mr. G was not admitted to rehabilitation; however, he was assessed 8 months after his stroke. He said that although he was very confused, he still returned to work. He asked his family for help, but did not receive support. Mr. H waited slightly more than a week before he was admitted to rehabilitation. He believes he was admitted because he had no family to care for him.

> Mr. H: But it was because I, I didn't, I was alone, and there was anybody um, there during the day, so they put me in um, I don't know where, the diabetes type people. Ah... to keep me in the hospital and to observe me and stuff like that.
>
> Interviewer: They provided you with rehabilitation, at the [hospital]?
>
> Mr. H: Ah, no they did do testing though, and, and, um you know they check your arteries...
>
> Interviewer: Right.
>
> Mr. H: ...check your heart Umm, they did a couple of scans and stuff like that, yep.

> Interviewer: So, did you go directly to the [Rehabilitation hospital] after that?.
>
> Mr. H: No, my brother did come over [from] BC and he stayed with me for about a week and half and then I got into the [Rehabilitation Hospital], cause I was alone. (Mr. H, page 8).

Compared to Mr. H, Mr. G has struggled at work and his activity levels continue to deteriorate. Mr. H feels he is continuing to thrive at work, in large part because he has received ongoing support from his psychologist. Mr. E has not returned to work, but says he is back to 70% of his pre-stroke activities. Professional support facilitated access. Mrs. B did not think she would have resumed playing golf without the recreation therapist presenting the opportunity and lessons. Similarly, Mr. D said that without the SCLS worker, he would not have the confidence to go out.

The comparison between participants demonstrates that in resumed activities there was more access to opportunities. This may suggest that that these participants likely could be more active, with access targeted to their goals.

Inclusion

Social inclusion was related to resumption of activities while social isolation was more common when participants had difficulty resuming their activities. Participants with the most inclusion (Mrs. B, Mr. E, Mr. F, Mr. H, Mr. I, and Mrs. J) seemed to have resumed a greater number of activities generally, and were pleased with their participation. Inclusion was partly related to opportunities to participate, as was the case with Mr. H’s work. They wanted him back at work, “I’m kind of specialized and that's why they wanted me back right away. There was nobody to do the work” (Mr. H, page 14). However, his immediate supervisor was also understanding and encouraging because his father-in-law had a stroke.

Inclusion increased activity by confirming participants were still valued and that they had the ability and the right to participate. After the stroke, most people said they lacked confidence and worried about their ability to cope. As family, friends, and professionals included them in normal social situations and regular activities, participants' disability was back-grounded and what they could do was highlighted. For example, Mrs. B and Mr. F both talked about being scared to go out after they were discharged home. Going out into the community with friends, the recreation therapists, and SCLS workers enabled both to gain confidence in their abilities.

> When I got home and I had to walk with a cane, so but I wanted to go out and walk and get some but I was kind of ah scared ….of …. how do you say it, I could be a victim very easily cause I can see me walking with a cane and if I have a fight, I can't really defend myself. It took me quite awhile to ah, get out. I wouldn't walk very far from home and I get, I got my license fairly soon after I got out of Glenrose. I was driving about June my stroke was in January, so, so my driving was okay but I wouldn't go to…. the malls and stuff really bothered me (Mrs. B, page 16).

> Ah, kind of but you know it's my friends. They like, they don't look at me like there's something different. You know when I complained about, you know not being able to hit the ball, she says, "Boy you're just like the rest of us." You know so they, they're very encouraging, but they don't make me feel like, there's something wrong with me (Mrs. B, page 4).

It was very difficult for these stroke survivors to participate in activities if they were excluded. Lack of time, a society not set up to deal with the slower pace of people with disabilities, lack of knowledge about invisible impairments, and the stigma of disability all contributed to situations that stopped participants from pursuing activities. Often, they were not given the time they required to say what they needed to say or physically get into the action. Functional disability physically excluded more impaired participants from community centres or public buildings like restaurants. The general public, and sometimes even healthcare professionals, were not prepared to deviate from regular routines to accommodate participants' needs. Mrs. J believed that people do not want to think about disability, so they avoid it by excluding people with disabilities.

> J: And you get treated like an idiot once you had a stroke. You're ignored as a person, by the medical people, I mean you get medical care, but they don't talk to like you know anything. And you lose all your friends, who you thought were your friends. You feel off the face of the earth it seems.

> Interviewer: Why is that?
>
> J: I don’t know why, it’s one of the hardest things I had to deal with. I was in the hospital and I don't think half of them came to see me, ever. It’s too close to home for them, I think.
>
> Interviewer: Too close to home?
>
> J: Ya I mean it could happen to one person, it might happen to them, and I think that's scary (Mrs. J, page 3).

Participants who had bad experiences as they attempted to resume normal activities often avoided similar situations. For example, Mr. E said he just does not go to occasions or locations where there are many people talking and Mr. D rarely goes to restaurants.

> I think so because, it’s just so, so much, to juggle. (Pause) if you don’t speak quickly (pause) and your, you’ve perceived to being slow. And if your, not ah, quick and you’re not going to, (pause) people aren’t going to want to, going to want to be around you.
>
> They’re [restaurants] in a hurry to get me seated and that and their tip and ah out so they can get the next people seated. It’s, the rhythm and breaking up the rhythm. The manager wants to, (cough) excuse me, get as many seatings as possible and ah if I’m walking slowly it’s ruining their rhythm. And old people do not leave big tips, cause they don’t drink and that’s where the management makes a lot of their money, most of their money. Profit margin is, is in the booze, right (Mr. D, page 24).

Practical help

All participants required practical help to complete tasks they physically or cognitively could not accomplish. But, they also needed to be able to do as much of the activity as they could to gain skills and confidence in their abilities. More activity, more complex activities, and satisfaction with participation were associated with appropriate levels of practical help. When too much was done for participants, or they were left completely to their own devices, they did not resume as many activities. Moreover, if participants were overprotected they could not do activities. For example, Mrs. B’s father would not even let her butter her own toast.

Appropriate levels of practical support enabled participants to complete as much of the activity as possible and receive help when necessary. Resuming golf, sitting on a condo board, going fishing, to church, and to work can be attributed to this type of support. In contrast, in the non-resumed activities participants had been left on their own or provided too much protection and support.

Summary of Compared Activities

To summarize, as participants tried to resume the non-resumed activities more often they proceeded on their own without help from family, friends, or professionals in the healthcare system. In non-resumed activities practical help, services, and support were less accessible or not as relevant to participant's goals as they were in resumed activities.

Inclusion was a significant factor in resuming activities. Inclusion enabled participants to normalize their disability through participation. They felt like they belonged in the situation and that it was acceptable to as they were able to participate.

4.8 Summary

The first purpose of this research was to describe the barriers and facilitators to stroke survivors' activities using an ecological approach. The findings indicate that the ecological model was useful as a framework to clarify barriers and facilitators to survivors' choice of and participation in activities. The findings clarified how social and environmental factors influenced the participants' choices and decisions about activities. Comparing the two selected activities (resumed and not resumed) revealed little difference between activities but surprisingly it did reveal that complexity of activities seemed to be related to disability level. For their non-resumed activity, it seemed that these participants chose activities that they believed they might be able to resume. This seems to fit with the process participants use to resume activities after stroke. However, scaffolding from task to activity to more complex activities depended on access and opportunity.

Access and social participation in activities were tied to how participants were positioned socially by others. Social inclusion, being accepted as they were, helped participants to normalize their disability, increased their confidence to try activities, and improved their satisfaction levels. Scaffolding to, and participating in, activities was the route through which participants developed a positive post-stroke identity. Especially when they first returned home, participants lacked confidence in their ability to negotiate social situations. Inclusion by family, friends, and people in their environment who positioned them as capable people gave participants activity opportunities as well as the confidence to proceed. Being able to participate reinforced that they were "contributing to… society" (Mr. D, page 27) or had a position in society.

The data analysis revealed that participation was a nested process where the elements, access to opportunity, social inclusion, and practical help needed to be integrated so that they were supportive of each other. These elements threaded through multiple systems levels. Navigation among organizations and system levels was difficult for these participants. Participants managed because they received significant support and practical help from family or from health or community professionals.

Comparison of resumed and non resumed activities revealed a significant gap in support for people with moderate and mild stroke. Access to services and supports was based on level of disability.

CHAPTER FIVE

DISCUSSION, LIMITATIONS, CONCLUSIONS AND IMPLICATIONS

5.0 Discussion

The findings indicate that some stroke survivors aged 50 to 70 years can become active again—even after a very large disabling stroke. A total of 9 individuals were interviewed for this study, three with mild strokes, three with moderate and three with severe strokes. Stroke leaves people with a wide range of physical, cognitive, hearing, vision, memory and communication impairments. Severity of stroke and amount of impairment is often related to stroke survivors' failure to resume personally meaningful activities (Clarke & Black, 2005; Desrosiers et al., 2006; Rochette et al., 2007). The correlations between functional outcomes and measures of activity and participation tend to be modest (Mercer, Freyburger, Chang, & Purser, 2009).

The definition of stroke severity, mild, moderate or severe varied between studies (Gosman-Hedstrom, Claesson, & Bolmstrand, 2008; Granger et al., 1993; Rochette et al., 2007; van Swieten et al., 1988; Wilson et al., 2002). In hospital, severity is rated by health professionals on the National Institutes of Health Stroke Scale [NIHSS] (Adams et al., 1999), the Canadian Neurologic Scale [CNS] (Rochette et al.) or on functional scales like the Barthel Index (Gosman-Hedstrom, Claesson, & Blomstrand, 2008), the Rankin Scale (Rankin, 1957), and the Functional Independence Measure [FIM] (De Haan et al., 1993). Level of disability is one of the criteria used to determine rehabilitation admission and access to disability supports (Edwards, Hahn, Baum, & Dromerick, 2006; Granger, Cotter, Hamilton, & Fiedler, 1993; Timbeck & Spaulding, 2003). Generally, a FIM of below 40 is considered severe, 40 to 80 or 100 as moderate, and above 80 or 100 as mild (Rochette et al., 2007). A Modified Rankin Scale score of one or two is considered mild, three moderate, and four or five moderately severe or severe (Slot & Berge, 2009; van Swieten et al., 1988; Wilson et al., 2002).

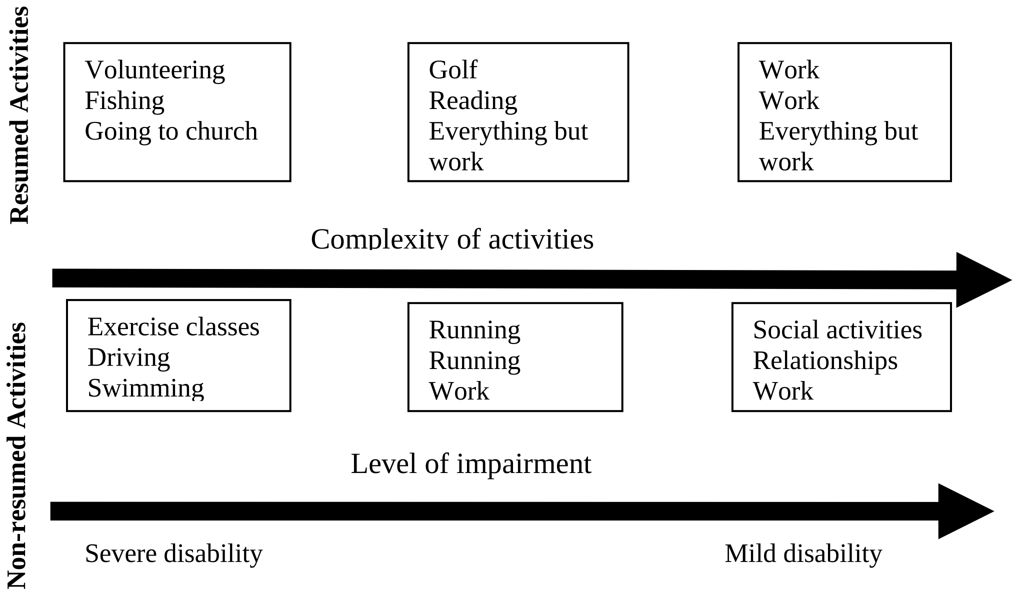
In this study, the participants' descriptions of their stroke were used to classify the level of severity. Three men maintained they were told by health professionals they had mini or mild strokes. They had no physical disability from stroke but did have fatigue, problems multitasking, and mild aphasia. Two men and one woman asserted their strokes were severe. They spent nine months to a year in rehabilitation and continue to require help with dressing and bathing. The two women and the one man classified as having moderate strokes had less use of one arm and more noticeable difficulty with speech. The classification system in this study is similar to other studies using the Modified Rankin structured patient interview (van Swieten et al., 1988; Wilson et al., 2002) or the Public Perception of Stroke Disability Scale (based on the Modified Rankin Scale) (Slot & Berge, 2009). Copies of these rating scales are included in Appendix J.

All but two of the participants said they were continuing to recover more functional ability and engaging in more activities of their preference. This is surprising considering that in the majority of studies, the functional health and activity of stroke survivors has continued to decline (Dhamoon et al., 2009; Mayo et al., 2002; Roth & Lovell, 2007). Health professionals and stroke survivors, alike, tell stories about people who make remarkable recovery from stroke or who continue to live active lives despite significant disability (Roman, 2008). Certainly, one question underlying this study was, “Why do some people thrive after stroke and others do not?”

At the individual level, more severe physical and cognitive disability is believed to limit people's ability to participate (Belanger, Bolduc, & Noel, 1988; Clarke & Black, 2005; Roth & Lovell, 2007; Salter et al., 2007; Wiles et al., 1998; Wiles, Ashburn, Payne & Murphy, 2004). Unquestionably, disability from stroke did make participation more difficult for the participants in this study. All participants said they had to struggle with fewer abilities than they had pre-stroke. These survivors asserted that any difference in capacity or facility that restricted them from participating in the same way as they had pre-stroke was limiting. At all levels of disability, mild, moderate, or severe, participants' response to limitations was to start where they were at and work towards the next task or activity level. The most disabled participant called it "scaffolding." Scaffolding is an apt name for the process. Participants related resuming small tasks like a couple of pushes on the bike pedals or being able to read a few words to re-gaining more complex activities, like walking to the mailbox or reading a whole book. But, the process of scaffolding involved more than moving from simple tasks to more complex activities. The resumed and non resumed activities seemed works in progress. Participants described scaffolding of activities in terms of a continuum, as they were able to do some task or activity they aspired to more complex projects. Going back to work illustrated this, being employed meant that improvement was required on tasks like writing reports and dealing with anxiety about relationships with colleagues. This is called a "response shift," changes in the meaning of one's self-evaluation of quality of life resulting from changes in internal standards, values, or conceptualization (Ahmed, Mayo, Wood-Dauphinee, Hanley, & Cohen, 2005). People can raise or lower their expectations. The most disabled participant's choice of driving as his non resumed activity is a good example of the upward response shift found in this study. He did not think he could resume driving because he had severe left side neglect. But as he has become more physically active and learned to read, he now thinks driving is a possibility. He has been successful at driving a quad at the hunting camp.

Certainly, in the activities participants chose to talk about there was a relationship between the activity complexity and level of disability. For both their resumed and non resumed activities, the most disabled participants chose less complex activities. Participants with moderate disability chose somewhat more complicated activities than the group with severe disability. Participants with mild stroke wanted their post-stroke activities and lifestyle to be as close to pre- stroke as possible. As the following figure illustrates, both the resumed and non-resumed activities became more complex with lower levels of disability.

Figure 5.1 Activity complexity continuum



It would seem that these participants were setting their goals based on what they consider to be personally achievable not necessarily what they have been told by health professionals.

At home, in rehabilitation, and in the community, participants maintained that they were prevented from getting involved in some of their undertakings because someone thought they were incapable of participating safely. Stroke survivors are prevented from trying activities (Hammel et al., 2007), given deterministic predictions about what they might achieve, or they are told their goals are unrealistic (Glass et al., 2004; Wiles et al., 1998; Wiles et al., 2004). Resuming activities after stroke has been described as a process of negotiating realistic goals and appropriate activities between survivors and their families, health professionals, and community professionals (Bendz, 2000). At all levels of disability, mild, moderate, and severe, participants who had positive support from families, friends, health professionals, or community workers to ‘go ahead and try’ (with appropriate support) were more active than participants who were not supported to make the effort or were prevented from trying because the activity was deemed risky. Based on these findings, professionals and families need to be careful about making deterministic predictions, telling the stroke survivor that their goals are unrealistic, or limiting the possibilities for survivor's participation.

Other studies confirm that stroke survivors have their own timetable and goals based on knowledge of their own circumstances (Barnard, Cruice, & Playford, 2010; Ellis-Hill, Robison, Wiles, McPherson, & Hyndman, 2007). Often stroke survivors downplay their real goals or don't tell others about their aspirations because other people think they are impractical or impossible to achieve (Bendz, 2000; Barnard et al., 2010). When professionals (Alaszewski, Alaszewski, & Potter, 2004; Barnard et al., 2010) or families (Evans, Connis, Bishop, Hendricks, & Haselkorn, 1994) believe the goals are unrealistic, they do not provide help.

Successful involvement in activities related to the degree other people were willing to assist and include survivors into normal social situations. Previous studies have stressed that stroke survivors' individual ability to adapt to disability, to maintain a sense of independence, and to adapt activities to their disabilities enables stroke survivors to participate (Becker, 1993; Becker, 1997; Clarke & Black, 2005; Haggstrom & Larsson-Lund, 2008). Participants in this study were not in control of many of their opportunities to participate. While they did influence whether they were invited to participate in activities by demonstrating motivation, working hard, and minimizing the disabling results of stroke, for the most part they were not in charge of what others thought of their requests for support, if they met the eligibility criteria, or whether they got admitted to the institution. Other people had the power to make those decisions. Participants did not have the control to determine if: they saw a doctor in emergency immediately upon arrival, whether they were admitted to rehabilitation and for how long, or if they qualified for disability supports. There are institutional rules and policies that determine who qualifies. They were reliant upon other people, institutional rules, and policies to facilitate their engagement.

One of the most striking findings was how participants completely lost their social position at the time of their stroke. Several participants maintained that people they had known for years now avoided them. Health professionals, who days before treated them as colleagues, ignored them post-stroke. Others were taken aback by the constant scrutiny of all their activities by health professionals and family. Participants were surprised by how much of their own status was tied to their pre-stroke activities and how difficult it was to regain a positive new reputation now that they were treated as disabled.

Many authors have asserted that when people have a stroke, they are separated from the person they were pre- stroke, they lose their functional ability and their identity (Becker, 1993; Ellis-Hill, Payne, & Ward, 2000; Seacrest & Thomas, 1999). Some studies link loss of identity to role loss caused by the individual’s inability to carry out the activities associated with the role (Clarke & Black, 2005; Dowswell et al., 2000). Recent work has questioned both of these findings. Some authors agree that following any life changing event, people’s sense of self is fluid (Guise, McKinlay, & Widdicombe, 2010; Ellis-Hill, Payne, & Ward, 2008; Rittman et al., 2007). It is not the survivor’s disability, but how survivors are treated by health professionals and other people that has the most powerful effect on people’s sense of self (Guise, McKinlay, &Widdicombe, 2010; Ellis-Hill, Payne, & Ward, 2008). It is how they are socially positioned.

Participants in this study did not talk about an altered identity. Rather they spoke about how others treated them, how that treatment affected their ability to participate, and how participation affected their self esteem. When participants were positioned as capable by family, friends, and professionals, they were more successful in resuming activities. They linked their inferior social position directly to inability to resume activity. If they were positioned as the same person as they were pre-stroke, capable of contributing, and they were included into normal social situations they had opportunities to participate. Conversely, when they were positioned as disabled, their deficits and disabilities fore-grounded, they described the many ways in which they were ignored and excluded.

A position provides the person with certain ascribed rights. A doctor can prescribe medication or the cleaner has the keys to enter the offices in the building (Langenhove & Harré, 1999). Within the local institutional and moral order, entire social groups, such as women, people with disabilities, or people of color are relegated to “specific discursive relations and social practices,” which create positions or stereotypes that they are expected to assume (Albrecht, Seelman, & Bury, 2001; Boxer, 2002; Weedon, 1987, p. 22). Identity is developed interactively from the culture of the environmental context, being in the world, and participating in activities in the company of others (Bendz, 2000; Burton, 2000; Glass et al., 2004; Kitwood, 1993; Sabat, 2002).

After stroke, health professionals described people by their deficits whereas individuals portray themselves as having a position in society that they wish to re-assume (Anderson & Marlett, 2004; Bendz, 2000). Professionals want to ensure that people are realistic about their life with disability and accept their situation (Glass et al., 2004; Wiles et al., 1998; Wiles et al., 2004). However, for people with disabilities accepting the status quo may mean being resigned to being treated differently, excluded from usual social contexts, and accepting fewer activities (Albrecht & Devlieger, 1999; Albrecht, Seelman, & Bury, 2001; Oliver, 1990). Certainly, people with disabilities have long argued that exclusion and societal attitudes about their acceptable activities are the biggest barriers to their participation (Davis, 2000; Oliver, 1999).

In this study, across all levels of the ecological model (Bronfenbrenner, 2005), social inclusion enabled people with stroke disability to overcome fear of being vulnerable, the stigma of disability, and beliefs about what a person with stroke should be able to achieve. Most importantly, it opened up new storylines and positions for participants. Participants became ‘one of the crowd’ again, the friend they had been pre-stroke or a member of the board, rather than “the other” --the person identified by stroke and stroke disability. It enabled their participation. This has been the aim of the disability movement (Oliver, 1999). The International Classification of Functioning Disability and Health [ICF] (WHO, 2001; WHO, 2002) emphasizes that disability is not just a function of individual disability, but equally the facilitating or hindering effect of the environment.

Analysis using the ecological model exposed multilayered facilitators and barriers to participation. Barriers intertwined and threaded through multiple levels of influence, with factors at different systems levels each having an impact on participant's choice and control in their daily lives. Participants explained that something as simple as buying a scooter to go to the store to get groceries meant: getting approval from a health professional, providing proof of financial eligibility to qualify for provincial healthcare assistance, and having the personal finances for a co-payment. Additionally, if the person qualified as disabled under federal government tax laws, there are tax credits, but if they used registered retirement savings funds to make the payment, that triggered other taxes and affected eligibility for income benefits back at the provincial government level. When any one element was delayed or missing participants' activities were curtailed and their aspirations blocked.

Navigating through health, community, and government systems without help from other people was difficult for participants in this study. This finding is corroborated by many other studies (Bhogal et al., 2003; Brown et al., 2004; Haggstrom & Larrson Lund, 2008; Hammel et al., 2007; Mold, Wolfe, & McKevitt, 2006; Rimmer, Wang, & Smith, 2008). Without significant help from families or others, stroke survivors have little choice but to be inactive (Clarke & Black, 2005; Mayo et al., 2002). A key finding in this study was that these participants became active because they received the appropriate level of support from families, friends, and professionals.

Most of these participants are thriving. The majority (but not all) was engaging in new and old activities and occupations quite successfully. Much of this can be attributed to their enriched home and community environments. These survivors had access to opportunities to participate, were included by their family and friends, and received appropriate practical support to reduce the gap between their functional abilities and task demands. In contrast to the other studies that showed most stroke survivors were inactive after discharge home from rehabilitation (Mayo et al., 2002; Roth & Lovell, 2007), the majority of these participants spent significantly longer time in-patient rehabilitation.[4] Moreover, they continue to receive ongoing support from recreation therapists, psychologists, and community skills professionals who actively promote engagement in activities. These professionals helped participants to navigate the health and community systems, increased survivors' capacity to manage, and to find natural supports in the community.

The enriched environments of these participants are unusual. Very few interventions promote the health of this population (Hallberg & Kristerisson, 2004), outpatient rehabilitation services are limited (Mold, Wolfe, & McKevitt, 2006) as are community skills training (Roth & Lovell, 2007). Once people with stroke are discharged from rehabilitation, the focus for people with moderate or severe stroke has been on chronic disease management and on secondary prevention for those with mild stroke or TIA (Edwards et al., 2006). The value of enriched environments in promoting health is not a new idea. That is the focus of Bronfenbrenner's ecological model. Enriched environments are crucial to developing children (Bronfenbrenner, 2005) as well as capable of increasing brain plasticity and improving brain function in older adults (Mahncke, Brownstone, & Merzenich, 2006). Moreover, there is a significant body of literature from animal studies of stroke, that stroke-induced animals recover significantly more function in rehabilitation environments where they are actively engaged in functional intensive activities (Biernaskie et al., 2004; Hicks et al. 2007). Given the healthcare costs to manage the health of this population, intervening to promote activity and health may be cost effective (CIHI, 2006; 2007; Howard, Nieuwenhuijsen, & Saleeby, 2008; HSFO, 2007).

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[4] In this study, the mean inpatient rehabilitation stay was 6.22 months (range 0–12 months). In Ontario, total length of stay (Mean, median in brackets) in in-patient rehabilitation was: 2003, 38.7 (34) days; 2004, 36.4 (31); 33.5 (29) (OSS Stroke Evaluation Advisory Committee [SEAC], 2007).

The contrast between participants resumed and non-resumed activities did point out imbalances between the services and supports for those with severe stroke and those with mild or moderate stroke. People with severe stroke benefitted from long rehabilitation stays and many ongoing professional health system and community supports, whereas those with mild or moderate strokes received much less rehabilitation. Moreover, they did not receive the same level of support once discharged from hospital.

One participant received secondary prevention healthcare but no rehabilitation. Fifty to 70 percent of stroke survivors, who have had mild or moderate strokes are discharged home with little support to resume previous activities (Heart and Stroke Foundation of Ontario, 2007; Wolfe, Baum, & Connor, 2009). This is likely because individuals with mild strokes are expected to achieve significant functional recovery without intervention (Edwards, Hahn, Baum, & Dromerick, 2006). Healthcare assessment and treatment need is based on functional disability and ability to perform the basic skills required to live at home (Wolfe, Baum, & Connor, 2009). Although they do well on the typical functional assessments or activities of daily scales, mild stroke has a negative impact on their usual activities. Studies on mild stroke document decreased leisure activities (Rochette et al., 2007), diminished abilities in employment or other productive activities and reduced social activities (Edwards et al., 2006). Mood disturbances (anxiety and depression) are reported in more than 70% of mild stroke survivors (Carlsson et al., 2003).

The comparison of two mild stroke survivors in this study, one who received rehabilitation services and the other who did not would suggest that mild stroke survivors might benefit from professional support. Although fully physically independent, the participant who was not admitted to rehabilitation was complaining of many of the same cognitive and psychological problems identified by Carlsson et al. (2003) and Edward et al (2006): persistent fatigue, memory problems, anxiety, and difficulty keeping up at work. Similar to Rochette et al.’s participants (2007) this participant’s activity levels continued to decline in contrast to the participant admitted to rehabilitation had similar disabilities after stroke, but professional support enabled adaptation to anxiety and successful return to work. There has been little research on how mild stroke affects survivor's activity levels.

Some participants with mild to moderate stroke were disappointed because rehabilitation and community programs were geared to achieving basic functions or keeping people busy. They believed that rehabilitation and community programs should be designed to help people return to their former lifestyle, not simply to basic activities. Currently services are based on what health professionals think patients will achieve with limited health budgets (Barnard, Cruice, & Playford, 2010; Ellis-Hill et al., 2007; Mold et al., 2006; Tyson & Turner, 2000). Rehabilitation times are shorter (SEAC, 2007). The goal of rehabilitation is not return people to a pre-stroke level of functioning, but to enable people manage to live safely at home (Barnard, Cruice, & Playford, 2010; Ellis-Hill et al., 2007; Mold et al., 2006; Tyson & Turner, 2000).

Once discharged home from hospital, participant's biggest grievance was that their access to activities and supports (rehabilitation, employment, and even community centers) were restricted by institutional rules based on disability level. Regulations governing income supports, long-term disability, and workplace support for people with disabilities were particularly restrictive. Participants believed that if they sought any employment or even volunteered extensively, they would be deemed capable of working and would lose disability income benefits. They want to work, but gave a list of factors that made employment difficult. They could work, but at a much slower pace. Employers were not willing to take a chance on hiring them. If they did get hired, they received a lower wage and were the first one laid off. If they worked part-time, earnings were deducted from disability income, leaving them with little incentive to work. Moreover, those that were working were worried they would be the target of downsizing if others knew about their stroke. Other studies have pointed out that government employment polices to assist people with disabilities do little to change perception of disabled persons employability or help them to become employed (Piggott, Sapey, & Wilenius, 2005; Shier, Graham, & Jones, 2009). In fact, in Calgary and Regina workplace environments were unwelcoming and employers discriminated against people with disabilities (Shier, Graham, & Jones, 2009).

Provincial income support for people with disabilities, the Canada Pension Plan Disabilities benefit, and disability tax credit are designed to ensure that people with disabilities do not live in poverty, but they also make sure that only people entitled to benefits get benefits. Decisions about who is disabled, who gets services, and what services they receive are made according to pre-determined general schedules in a fit-for-purpose manner (Leonardi & Chatterji, 2009). From the findings in this study, it would be helpful to advocate for policy changes to employment laws and disability supports. Currently, Canadian disabilities groups (Caledon Institute of Social Policy and the Council of Canadians with Disabilities) are advocating for a more flexible approach to disability incomes starting with a refundable disability tax benefit and a guaranteed income supplement for people for people with disabilities (Prince, 2008).

There has not been a concerted effort to improve participation and quality of life after stroke. The main focus continues to be on acute care treatment and secondary prevention (Bhogal et al., 2003; HSFO, 2007). The findings in this study do imply however that quality of life after stroke is integrally tied to participation in meaningful activities and inclusion in the community. The 50- to 64- year-old baby boomers in this study might be thought of as the “early adopters” of stroke[5] (Foot, 2001; Rogers, 1995). Early adopters provide significant direction on how to refine the future (Rogers, 1995).

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[5] The mean age of stroke in Canada is 72. The mean age of stroke for this group was 55.3; 16.7 years younger than the average age of stroke (SEAC, 2007).

Much of the research in stroke had been done at the individual level. There been little research to determine how features of the stroke, experience of the individual, and their environmental context interact to enable people with disabilities to live active lives. In this study, use of the ecological model demonstrated that individual disability and individual motivation are only two factors in community re-engagement. Policies, attitudes to disability, and availability of supports, and services at the mesosystem and macrosystem levels played an equal but less acknowledged role in individual engagement in meaningful activities. This reinforces the value of the ecological model and qualitative research methodology in understanding the experiences of stroke survivors. It is a useful framework by which to identify the factors that influence survivors’ activity choices.

5.1 Limitations

Like many qualitative studies in stroke, this study has a limited sample size and is based on a single interview (McKevitt, Redfern, Mold, & Wolfe, 2004). Sampling was done to select participants with different levels of disability. In this study, the categorization of mild, moderate, and severe was not based on the usual functional indexes or stroke scale scores, but on the participants’ own description of their stroke. If Canadian Neurological Scale hospital admission scores or Functional Independence Measure discharge scores had been used, participants might have been classified differently. However, these scales weight physical disability or ability to perform the basic activities of daily living heavily and cognitive disability and psychological problems like fatigue and depression that do affect community participation levels are not taken into account by these scales (Guise et al., 2010; Rochette, Desrosiers, Bravo, St-Cyr/Tribble, & Bourget, 2007).

Although participants could be categorized into three disability levels (mild, moderate, and severe); participants with mild stroke may not be representative of community-dwelling survivors. All but one of the participants, were admitted to in-patient rehabilitation. Depending on location (urban/ rural), about 20% of patients are admitted to in-patient rehabilitation. People in urban centers are much more likely to be admitted to rehabilitation (SEAC, 2007). About 50% to 70% of stroke survivors are discharged directly home from emergency or acute care hospitals[6] (Guise et al., 2010; Rochette, Desrosiers, Bravo, St-Cyr/Tribble, & Bourget, 2007). Consequently, the sample is not representative of stroke survivors living in the community.

The study sample was not selected to represent all stroke survivors, but rather baby boomers (the large surge in the population of people born between 1946 and 1964) (Foot, 2001). These participants are likely representative of their generation, and the qualitative methods used in this study do provide an in-depth understanding of their experience trying to resume activities post-stroke. Comparison between participants suggests that on their own, without assistance, survivors with mild and moderate strokes experience more barriers and are less likely to resume activities of their choice due to barriers at all levels of the ecological model. The small sample size and categorization of stroke severity precludes stronger conclusions.

5.2 Conclusions and Recommendations

Stroke survivor’s community participation is heavily influenced by social positioning at all levels of the ecological model. People with stroke lose their social position when they have a stroke. Social inclusion enabled participants to develop a new position in society. People with stroke are normally discharged home into the community with little follow-up and support. Roth and Lovell (2007) have suggested that community skills training may be beneficial for this population. Based on the results of this study, community skills training to help individuals re-engage in the community would be beneficial. However, this only continues to address stroke community integration and stroke survivor’s lack of activity at the individual level. A broader health promotion approach could

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[6] In 2006 in Ontario, 45.2% of people arriving at emergency with stroke or TIA are discharged home from the emergency department; 21% (range 12% to 30%) of the people who are discharged alive from acute care are admitted to in-patient rehabilitation (SEAC, 2007).

identify leverage points amenable to change, work at increasing awareness of the needs of stroke survivors, and address policy barriers that prevent people from engaging in meaningful activities.

Health promotion is a comprehensive approach to health that includes physiological functioning, emotional functioning, social functioning and inclusion. Interventions that use a health promotion ecological model are more effective at improving the health of a larger number of people because they target all levels of the ecological model (Smedley & Syme, 2000). Rehabilitation and community integration research can learn from this approach. If stroke survivors, professionals, researchers, and policy makers expanded the focus from individual physical functioning to addressing some of the social and policy barriers that restrict survivors' activity choices, it is more likely to improve the health of more stroke survivors. People with disabilities belong in the community. Inclusion is a health promotion strategy that increases belonging.

The ecological model and situational analysis are useful to uncover factors at other system levels that restrict or expedite individual actions. The results of the present study are similar to previous studies (Clarke & Black, 2005; Haggstrom & Larsson-Lund, 2008), but other authors related inactivity to individual deficits (e.g., the individual cannot drive rather than lack of disabled public transportation). Situational analysis and the ecological model introduced alternate ways of thinking about problems, specifically how individual negotiations may be affected by institutional and power relationships in the context (Bronfenbrenner, 2005; Strauss, 1993; Clarke, 2005).

Stroke has not been a priority with healthcare policymakers. Compared to heart disease and cancer, research and medical treatment stroke research and medical treatment are underfunded (Pendlebury, 2007). In the neurological disease category, stroke research receives only half the funding allocated for Alzheimer's (Broderick, 2004). Stroke is seen as a disease of the old, for which little can be done, and there is a bias against funding for diseases of aging (Broderick, 2004). During the present study, it was interesting to note that participants themselves mused that stroke was not a priority because it is a disease of the old. There has been little recognition that stroke also affects young people (Pendlebury, 2007). Community reintegration has received even less funding than research, acute medical treatment, and rehabilitation (Bhogal et al., 2003; HSFO, 2007). Given that managing stroke is expected to be costly, further research is warranted to determine if efforts to promote healthy engagement in activities can improve quality of life and reduce the management costs of chronic stroke-related impairment.

The results of this study suggests that two areas are under-investigated: (1) community integration and health promotion for Canadians discharged home after stroke; and (2) the population of people with mild stroke discharged directly from hospital without rehabilitation are less active than people with similar strokes who receive rehabilitation. Researchers could explore the following:

- The impact of community and policy support for people with moderate or mild stroke to reach higher level goals like return to work;
- If the activity levels of people with mild stroke are significantly affected, and does professional support improve activity levels;
- The effects of community skills training and navigational support on stroke survivors activity levels; and
- A community scan of supports available to stroke survivors to determine how they could be integrated in to make community navigation easier.

5.3 Implications

Improvements in medical technology are increasing the number of mild to moderate stroke survivors. Given the costs of re-hospitalization and institutionalization of this population, methods of promoting health after stroke are urgently needed. The new challenge that researchers, clinicians, and policymakers face is ensuring good quality in these added years. Improving the chances for people discharged home into the community to find meaningful productive or leisure activities should be a priority for future research.

Individual medical and rehabilitation interventions are and will remain important. Unquestionably, rehabilitation was responsible for the successful return home of many people in this study. However, promoting inclusion of people with stroke and stroke related impairments through changing attitudes and public policy has the potential to improve the lives of many Canadians with disabilities. Stroke survivors themselves should be included in the process rather than having proxies, families, or professionals speaking for them. A health promotion approach for people with disabilities must also be included in research priorities and on policy agendas.

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Appendix A: Letter Seeking Approval to Display Poster and Distribute Flyers

[On Letterhead]

<u>Title of Research Study:</u> Community Living After Stroke: An Ecological Approach

Principal Investigator(s): Dr. Kyle Whitfield
Faculty of Extension
University of Alberta

Sharon Anderson
Centre for Health Promotion Studies
School of Public Health
University of Alberta

[Name, title, and address]

Dear [name],

Many stroke survivors and some research (Mayo et al. 2002) says survivors don't know what to do when their rehabilitation services end. The Canadian Stroke Network has funded a community integration research program called "Getting on with the rest of your life after stroke" to determine if it is possible to address this gap with a community group program. But anecdotally, across Canada many of these programs have had difficulty recruiting participants. It is not clear why.

I want to understand the role that choice, barriers, and facilitators play in stroke survivors' choice of daily activity by answering the question:

> Based on an ecological model, what are the perceived barriers and facilitators associated with the everyday choice of activities, of those who have had a stroke between 1-6 years ago? And are there differences and/or similarities between two activities, one that stroke survivors have not yet resumed or had to give up and another activity they have continued?

If possible, I would like to recruit participants for this study at your Capital Health facility. I have enclosed a short summary of the research and the NATRAC Operational Form. If you and your team agree to allow study participant recruitment, I would ask you to

1) Display a poster where it is visible to stroke survivors using your services and
2) Ask you and your staff to distribute recruitment letters to stroke survivors who might participate in this research

Stroke Survivors will be eligible for the study if they:

- Had a stroke 1 to 6 years ago.
- Are 50 and 70 years of age.
- Can understand spoken English.
- Are living at home (not in long term or institutional care).

I will be happy to share my research results with you and your group at the completion of the study.

I will call you next week to answer any questions, and if you agree to help recruit participants, we can arrange a suitable time for me to drop off the posters and recruitment letters. I look forward to speaking and meeting with you.

Sincerely,

Sharon Anderson
Graduate Student
Centre for Health Promotion
School of Public Health
The University of Alberta
780- 628-4222 or Cell phone: 780- 863-3260
email sdanders@ualberta.ca

This project has received Health Research Ethics Board approval.

Dr. K. Whitfield is supervising this graduate level research and can be contacted at 780-492-0165 or by email at kyle.whitfield@ualberta.ca

Appendix B: Abstract of Research Proposal

Introduction: The success of acute medical services in increasing stroke survivors’ length of life is indisputable. However, ensuring that these added years are of good quality is now a challenge that researchers, clinicians, and policy-makers must address. Despite significant knowledge about the lack of participation in meaningful activity post-stroke, there have been few assessments of how stroke survivors structure their daily lives and what factors influence their choices, priorities, and goals. Objectives: This study seeks to understand the role that choice, barriers, and facilitators play in stroke survivors’ activity selection of by answering the question and sub-question: Based on an ecological model, what are the perceived barriers and facilitators associated with the everyday choice of activities, of those who have had a stroke between 1-6 years ago? And are there differences and/or similarities between two activities, one that stroke survivors have not yet resumed or had to give up and another activity they have continued?

Methods: This cross sectional exploratory study will use a semi-structured interview to survey stroke survivor’s accounts of an activity they have resumed post- stroke and another that they have had to give up. They will be asked to describe the factors that they perceived facilitated or obstructed their activity choice, engagement, and disengagement. Data Analysis: Grounded theory will be used to analyze relationship between barriers and facilitators and patterns of activity engagement. The resulting theoretical categories will be compared for fit with the health promotion socioecological model.

Appendix C: Recruitment Poster

Community Living After Stroke: An Ecological Approach

Did you have a stroke 1 to 6 years ago?

Would you like to participate in research?

Are you 50 to 70 years old?

A graduate student from the University of Alberta is conducting a study to understand the role that choice, barriers, and facilitators play in stroke survivors' choice of everyday activities. In particular, I want to know:

Are there differences and/or similarities between two activities, one that you had to give up and one activity you continued?

What will you have to do? Meet with the researcher for about 60 to 90 minutes.

More information:
Sharon Anderson
780-628-4222 or email:
sdanders@ualberta.ca

Dr. K. Whitfield is supervising this graduate level research and can be contacted at 780-492-0165 or by email at kyle.whitfield@ualberta.ca.

Appendix D: Telephone Recruitment script

Telephone Script to Team Leaders

Hi, [Name of Team Leader]

My name is Sharon Anderson, from the Centre for Health Promotion Studies at the University of Alberta. I mailed you a letter last week about recruiting stroke survivors 1 to 6 years post-stroke to participate in a research study. Community Living After Stroke: An Ecological Approach This study seeks to understand the role that choice, barriers, and facilitators play in stroke survivors' activity selection of by answering the question: Based on an ecological model, what are the perceived barriers and facilitators associated with the everyday choice of activities, of those who have had a stroke between 1-6 years ago? And are there differences and/or similarities between two activities, one that stroke survivors have not yet resumed or had to give up and another activity they have continued?

Could you distribute recruitment posters and letters to stroke survivors for me?

If team leader agrees:

> "I will drop off the posters and letters to you this week. Is there a particular time when I can meet you or shall I give them to the receptionist?"

If they are not interested:

> "Thank you for considering this. I know how busy everyone is."

Dr. K. Whitfield is supervising this graduate level research and can be contacted at 780-492-0165 or by email at kyle.whitfield@ualberta.ca

Appendix E: Informed Consent

[On letterhead]

Consent to Participate in Research

Dr. K. Whitfield is supervising this graduate level research and can be contacted at 780-492-0165 or by email at kyle.whitfield@ualberta.ca

Title of Research Study: Community Living After Stroke: An Ecological Approach

Principal Investigator(s): Sharon Anderson
Graduate Student
Centre for Health Promotion
School of Public Health
The University of Alberta

Background: Over 80% of people survive stroke but the majority do not fully recover. Most people have some disability. Some people have trouble finding activities that they can do after stroke. This may be because people don't have the support they need, information about activities, or because they can't find transportation to get to activities.

Purpose: This study seeks to understand the role that choice, barriers, and facilitators play in stroke survivors' activity selection of by answering the question: Based on an ecological model, what are the perceived barriers and facilitators associated with the everyday choice of activities, of those who have had a stroke between 1-6 years ago? Specifically, this study seeks to answer this sub question: And are there differences and/or similarities in the two activities that they had to give up and those activities they continued?

Procedures: Participating in this study will involve: One meeting that will take 60 to 90 minutes of your time.

The researcher will ask a few questions about your background. For example, "When were you born?", "Are you married?" Then, you will be asked about what you did in the month prior to your stroke. The researcher will want to know what makes it easy or difficult for you to do an activity you returned to and one you have yet to resume.

Possible Benefits: Just talking to someone may make you more aware of the things that help you with your everyday activities.

Possible Risks: You could find discussing what activities you cannot do distressing. You may become tired during the interview. If you become distressed or tired, you can stop participating in the study, you can take a break and continue, or we can arrange to continue the interview another day.

Confidentiality: Data collected as part of this study will be kept confidential. You during this study will not be identified anywhere by name, only by a code number. Any report published as a result of this study will not identify you by name.

Voluntary Participation: You do not have to participate in this research. You are free to withdraw from the research study at any time. If any knowledge gained from this or any other study which could influence your decision to continue in the study becomes available, you will be promptly informed.

Reimbursement: You will be given a small token of appreciation, a $5 gift card from a coffee shop at the end of this research to thank you for your time.

Contact Names and Telephone Numbers:

If you have concerns about your rights as a study participant, you may contact the Patient Relations Office of Capital Health, at 482-8080

or

the University of Alberta Health Research Ethics Office

213 Heritage Medical Research Centre (HMRC)

Edmonton, AB T6G 2S2
Phone: (780) 492-0302
Fax: (780) 492-7808

These offices have no affiliation with the study investigators.

Please contact any of the individuals identified below if you have any questions or concerns:

Sharon Anderson, Graduate Student, Centre for Health Promotion School of Public Health
Telephone Number 780-628-4222 or sdanders@ualberta.ca

Dr. K. Whitfield is supervising this graduate level research and can be contacted at 780-492-0165 or by email at kyle.whitfield@ualberta.ca

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CONSENT FORM Community Living After Stroke: An Ecological Approach

Part 1 (to be completed by the Principal Investigator):

Title of Project: Community Living After Stroke: An Ecological Approach

Principal Investigator(s): Dr Kyle Whitfield Phone number 780- 492-0165

Sharon Anderson Phone Number(s): 780-628-4222

Dr. K. Whitfield is supervising this graduate level research and can be contacted at 780-492-0165 or by email at kyle.whitfield@ualberta.ca

Part 2 (to be completed by the research subject): Circle Yes or No.

1. Do you understand that you have been asked to be in a research study? Yes No
2. Have you read and received a copy of the attached Information Sheet? Yes No
3. Do you understand the benefits and risks involved in taking part in this research study? Yes No
4. Have you had an opportunity to ask questions and discuss this study? Yes No
5. Do you understand that you are free to withdraw from the study at any time, without having to give a reason? Yes No
6. Has the issue of confidentiality been explained to you? Yes No
7. Do you understand who will have access to your records? Yes No

Do you want the investigator(s) to inform your family doctor that you are participating in this research study? If so, give his/her name ____________________________

Who explained this study to you? ____

I agree to take part in this study: Yes No

Signature of Research Subject ____

(Printed Name) ______________________________________ Date: ______________________

Signature of Witness _______________________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee___________________________ Date _____________

The information sheet must be attached to this consent form and a copy given to the research participant

Appendix F: Semi-Structured Interview Guide

Semi-structured Interview

Activities Pre-Stroke
For the purposes of this study, “activity” will be defined as any self-initiated, self directed activity chosen by study participants.

NB: Not all of the following questions will be asked of every participant

The following interview schedule reflects the topics and environmental settings that may be discussed. They are *representative only.* All of the following questions are not likely to be relevant to study participant’s activity choice. For example, activity selections like return to work or crocheting will require different questions.

Furthermore, the language will vary in response to the different ways participants discuss activities and whether the activity has been resumed or has not yet been resumed.

Introductory script to participants:

“I have wondered why some people seem to do better than others, even though they have similar strokes. I think you can help me. I'd like to ask you some questions about one activity that you are still doing since the stroke and one activity you haven’t done since your stroke."

“Thank you for agreeing to help me. I understand some things might be difficult to talk about. We can take a break or we can stop at any time.”

“First, can you tell me about the kind of things, that you did before your stroke? “You can tell me about any activities, leisure or work. “

Discussion about two specific activities:

“Now I’d like to ask you some questions about one activity that you have continued to do or resumed doing after the stroke and one activity you might like to do but haven’t started to do again yet.”

“Which activity would you like to talk about first?”

General question about chosen resumed activity

"What do you think helped you to do (activity) again?"

General question about chosen non- resumed activity

"What do you think has to happen for you to do (activity)?"

Possible Questions about Barriers and Facilitators to Activity

Environmental/ Physical Facilitators/ Barriers

***If activity is done in the home,* questions about home environment**

1. Can you tell me how (this activity) works (or might work) for you at home?
   (Follow- up question) Are there things around your house that you might change to make it even easier to do (activity)?
    a. (Follow-up questions): How did that work out? What might have prevented you from doing this? or Why haven't you made those changes?
        i. (Probes: What made that possible? or What makes it hard for you to do that? Could you tell me more about that?)
2. Is there anything that makes it hard?
    a. (Follow-up question) Does this change what you plan to do? Can you walk me through how it changes your plans? Why? or How so?

***If activity is done outside the home, in the community,* questions about community**

1. Can you tell me how your physical environment helps (hinders) (this activity)?
    a. (Follow-up questions) What makes it easy about (your building at work, the sidewalks, stores, or community centres) to get around to do (activity)? or Are there other physical barriers that might be a problem for you to do (activity)?
        i. (Probes: parking, stairs, curb cuts, ice snow, "Some people have said bright lights, too much noise, too many conversations make it hard, but it may be different for you. I really want to know about your experience?")
2. How have you gotten to (activity)? or How do you think you would get to (activity)?
    a. (Follow-up questions: Any other transportation? How do you arrange transportation?
        i. (Probes: How does that affect your plans? How does that make you feel?)
3. How much planning does it take for you to go out?
    a. (Follow-up questions) What makes planning easy? What makes planning hard?

            - i. (Probes: size of rooms, hallways, distances, bathrooms, maneuvering wheelchair, crowds? How did you manage this?)

4. What about friends, neighbors, or church, did they help you do (activity)?
    - a. (Follow-up questions) How was that helpful? Would you have preferred it to be different?
        - i. (Probes: How so?)
5. (*About Knowledge and Information*) How did you find out about (activity)?
    - a. (Follow- questions) Where did you get the information? (What might have made it easier/ better)?
        - i. (Probes: Did it help? Format? Would you prefer to have more or less information? Since you came home, what information have you been given about activities, services and supports that you might need?)

Questions about policy/societal context: How government policies/ societal context might change environments thus participation in (activity)?

1. In your experience, is there anything the city or other governments do to make it physically easier for you to do (activity)?

    (Probes: Are there any laws that might help this? Some people have said that handicapped parking laws are not enforced)

<u>Services and Supports</u>

***If activity is done in the home,* questions about services and supports at home**

1. What do family or friends do that helps you out with (activity)? Or what might family and friends do to help you with (activity)?

    (Probe: Can you walk me through how that works?)
    - a. (Follow- up question) Are there instances where someone really helped you out?
        - i. (Probe: How so? Tell me more?)
    - b. (Follow- up question) When you think back, are there times when you needed help to do (activity) and could not get it easily?
        - i. (Probe: Did that change what you do now? How you approach (activity) now?)
2. Can you think of anything (some services or supports) that would make it easier to do (activity)?
    - a. (Follow-up question) Where (or from whom) do you think you would get that?

***If activity is done outside the home, in the community,* questions about services and supports in the community**

1. What about (friends, neighbors, or coworkers), how have they helped (or might they help) you to do (activity)?
   a. (Follow- up question) Are there instances when they really helped out to do (activity)? or Could you have used other help to do (activity)?
      i. (Probes: Anything else? Or can you walk me through what that help might look like (or how that help might work)?)
2. Did you or do you get help from the health care system (Homecare, CRIS, Community Services, or Aids to Daily Living) to do (activity)? or Is there something the healthcare system should do to you to help you resume (activity)?
   a. (Follow-up questions) How has that helped? How might it help?
   b. Why do you think that has or hasn't happened?
3. What about work? Did they help you to do (activity)?
   a. (Follow-up question) How was it helpful? or What help might you need?
      i. (Probes: Time off, disability leave)
4. When you think about it, was there any support from an association or community center to do (activity)? How might support from an association or community center help you to re-engage in (activity)?
   a. (Follow-up questions) Why do you think that was (or isn't) available?
5. Can you think of other services or supports might make it easier for you to do (activity)?
   a. (Follow-up questions) Who (or what organization) should provide those?

Questions about policy/societal context: How government policy related to services and supports might help or hinder participation (in activity).

1. When you think about government, have you gotten any help to do (activity)?
   a. (Follow-up questions) Any laws that might help you out? (Example: Some people tell me that if people knew more about what happens after a stroke, there would be more rehabilitation but I am interested in your experience ….?)

<u>Attitudes</u>

If activity is done at home, questions about attitudes at home

1. What about your family? What do they think about you doing (activity)?
   a. (Follow-up questions) How did they (or could they) encourage you? Discourage?

    b. Have they been worried about you doing (activity)? Why might (that) be? or Why do you think (that)?
        i. (Probes: Has anyone tried to stop you? Why? How did that affect you doing (activity?)

***If activity is done outside the home, in the community,* questions about attitudes in the community**

1. How about your friends or (people in the stores, people in the community centre, your friends from work, at church) -- what do they think about your (activity) since your stroke?
    a. (Follow-up question) Encouragement? Has anyone treated you differently since your stroke?
        i. (Probes: How so? Can you give me an example?)
2. As you go out (into the healthcare system, community centre) how have you been treated when you do (activity)?
    a. Have you ever felt that people were critical of you when you tried to do (activity)? or Have you ever felt that you were criticized by others when you tried to do (activity)?
        i. (Probes: How did that affect what you chose to do?)

Questions about policy/societal context: How attitudes in societal context, government policy might relate to participation in activity?

1. How do you think Canadians feel about doing people like you doing (activity) after stroke? About people with stroke?
    a. (Follow-up question) How do you think that affected you?
        i. (Probes: Can you tell me more?)

Ending script to all participants

“This has been really helpful. Is there anything else you would like to tell me?
Since every stroke is different, there are may be other things that I should know……”

“If you think of anything else, you can give me a call.”

“Thank you very much. I really appreciate your help. Would you like a short summary of the research when I am done? If so I will mail you a copy.

Appendix G: Demographic Information Form

Demographic and Background Data Form

1. ID Number ______________
2. Date of Birth _________________Age _______________
3. Gender 1. Male_________2. Female____________
4. Marital Status
    - 1. Married
    - 2. Widowed
    - 3. Separated
    - 4. Divorced
    - 5. Never Married
5. Highest Level of Education Completed
    - 1. Master or Doctoral degree
    - 2. College or University degree
    - 3. Some College Training
    - 4. High School Diploma
    - 5. Partial High School (grade 10- 11)
    - 6. Less than junior high school
6. Living Arrangement
    - 1. Alone
    - 2. With Spouse
    - 3. With family, parents, children
    - 4. With hired attendant
    - 5. With friend
7. Are you currently employed?
    - Yes
    - No
    - Retired
8. What kind of work do/did you perform? ……………………………………………
9. When did you have your stroke? ………………………………………….
10. Do you know what part of your brain was affected by the stroke?

    Stroke Right brain

    Stroke Left Brain

    Stroke Cerebellum

Stroke Brain stem

11. How did the stroke affect you?

Aphasia –

- o Yes
- o No

Arm affected—

- o Right
- o Left

Leg affected –

- o Right
- o Left

Uses wheelchair or scooter: Yes No Able to walk: Yes No independently _____or with aid _____ name aid_____________

Memory Affected Yes No

Vision Affected Yes No

-

12. . Did you have any rehabilitation after your stroke? Yes No

- **If YES**, please give details ………………………………………………………………...
………………………………………………………………………………………………

Appendix H: Interview Analysis

(Questions from Roulston, deMarrais, and Lewis, 2003, p. 665) Interview
Keep reflective research journal on research process, process of interviewing and development of skills

1. How do you think you did with explanation of research purpose?
2. How do you think you did with explanation of the consent process and form?
3. How did the interview context enable or constrain the interview process?
4. How did you do in building rapport with the participant?
5. What kind of questions did you ask in the interview?
6. What kind of responses did you get?
7. How did your questions influence participants' responses?
8. Did you put possible responses into the questions?
9. Did you ask closed –ended questions? Open questions?
10. Did you use more than one question in your utterance?
11. How did you handle your wait time within the interview?
12. Was there overlapping talk in the interview? Interruptions?
13. Did you use continuers such as um, okay, mm-hmm?
14. Do you treat interviews as conversations? If so what was your input into the conversation?
15. Did you evaluate the participants' responses to your questions within the interview? If so how did the participant respond to this evaluation?
16. Were your interview questions focused on the purpose of the research and your research questions?
17. What would you do differently if you were able to do the same interview again?
18. What suggestions for improvement do you have for your own interview techniques?

Appendix I: Summary of Participant Characteristics

Self rated severity of stroke	Participant	Age	Sex	Date of stroke	Years since stroke	Cause of Stroke	Type and length of rehabilitation	Self Described effects of stroke	Able to drive
Mild	E	59	M	Jun. 17/ 2006	6	Not known	4 weeks in patient rehabilitation	No physical disability, mild aphasia, problems multitasking	Yes
Mild	G	58	M	Mar. 1, 2008	1	Patent foramen ovale	No in-patient rehabilitation, 8 sessions with psychology resident	Some memory loss, slight aphasia, no physical disability, fatigue, has returned to work	Yes
Mild	H	59	M	Feb. 2, 2007	2	Not known	4 weeks in-patient rehabilitation	Mild aphasia, emotionalism, loss of sense of humor, works full-time	Yes
Moderate	B	53	F	Jan. 24, 2006	3	Carotid artery dissection	6 weeks in-patient rehabilitation, 6 months outpatient rehabilitation, 2 weeks constraint therapy	Right arm affected, right leg slightly affected but able to run, mild aphasia, memory slightly affected	Yes
Moderate	C	53	F	Dec. 28, 2007	2	Not known	5 weeks in-patient rehabilitation	Has some movement of fingers in right hand, walks with AFO but significant spasticity in right foot, aphasia	Yes

Moderate	I	64	M	Nov.11 , 2007	1.5	Elevated Coumadin (INR 9.3)	4 weeks in-patient rehabilitation	Able to do everything but slower, slight right hand weakness and aphasia, works part-time for family	Yes
Severe	D	58	M	Mar. 5. 2005	4	Hemorrhagic stroke High blood pressure Overweight	3 months acute care, 3 months in-patient rehabilitation, 3 months slow stream in-patient rehabilitation	Walks 100 yards with quad cane and AFO/ sling for left arm, left side neglect, 3 different meds to control seizures	No
Severe	F	61	M	Nov 4, 2004	5	Hemorrhagic stroke Smoker/ high blood pressure	12 months in-patient slow stream rehabilitation	Walks 500 meters, up and down 14 stairs with quad cane and AFO, left arm is spastic, left side neglect, some memory loss	No
Severe	J	59	F	Nov 23, 2007	1.5	Protein C Clotting disorder	12 months in-patient slow stream rehabilitation	Walks with either AFO or WalkAide and cane, left arm is spastic, severe fatigue, left side neglect, some memory loss	No

Appendix J: Use of Rankin Scale to Define: Mild, Moderate, Severe Stroke

Modified Rankin Scale
0 = No symptoms at all
1 = No significant disability despite symptoms; able to carry out all usual duties and activities
2 = Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance
3 = Moderate disability requiring some help, but able to walk without assistance
4 = Moderate severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance
5 = Severe disability; bedridden, incontinent, and requiring constant nursing care and attention

van Swieten, J. C., Koudstaal, P. J., Visser, M. C., Schouten, H. J., & van Gijn, J. (1988). Interobserver agreement for the assessment of handicap in stroke patients. *Stroke*, *19,* 604-607.

Modified Rankin Scale Structured Interview (MRSSI)
0 = No symptoms at all; no limitations and no symptoms.
1 = No significant disability; symptoms present but not other limitations. Question: Does the person have difficulty reading or writing, difficulty speaking or finding the right word, problems with balance or coordination, visual problems, numbness (face, arms, legs, hands, feet), loss of movement (face, arms, legs, hands, feet), difficulty with swallowing, or other symptom resulting from stroke?
2 = Slight disability; limitations in participation in usual social roles, but independent for ADL. Questions: Has there been a change in the person’s ability to work or look after others if these were roles before stroke? Has there been a change in the person’s ability to participate in previous social and leisure activities? Has the person had problems with relationships or become isolated?
3 = Moderate disability; need for assistance with some instrumental ADL but not basic ADL. Question: Is assistance essential for preparing a simple meal, doing household chores, looking after money, shopping, or traveling locally?
4 = moderately severe disability; need for assistance with some basic ADL, but not requiring constant care. Question: Is assistance essential for eating, using the toilet, daily hygiene, or walking?
5 = Severe disability; someone needs to be available at all times; care may be provided by either a trained or an untrained caregiver. Question: Does the person require constant care?

Wilson, L. J. T., Harendran, A., Grant, M., Baird, T., Schultz, U. G. R., Muir, K. W., & Bone, I. (2002). Improving the assessment of outcomes in stroke: Use of a structured interview to assign grades on the Modified Rankin Scale. *Stroke*, *33,* 2243-2246.

Stroke outcome scenarios based on Rankin Scale (Slot & Berge. 2009)

Mild stroke (Modified Rankin Score 1)

- You have a slightly numb feeling in your non-dominant arm as a result of the stroke, but no significant loss of muscle strength.
- You have residual lower facial weakness on one side.
- You are fully independent of others in daily living after this stroke and can walk normally.
- You can think, read, and speak clearly.
- You are not incontinent.

Moderately severe stroke (Modified Rankin Score 3)

- Your non-dominant arm is paralyzed and you have reduced muscle strength in one leg.
- You can walk without assistance, but have a slight limp.
- You are independent in daily living, but require some assistance of others in cooking, shopping, and dressing.
- Your speech is slow and unclear, but understandable.
- You can think and read clearly.
- You are not incontinent.

Severe stroke (Modified Rankin Score 5)

- The right side of your body (arm and leg) is completely paralyzed.
- You cannot walk without assistance and need to use a wheelchair.
- You are bedridden most of the time.
- You need help in washing, dressing, and feeding.
- Your speech is slow and unclear, but understandable.
- You can think and read clearly.
- You are incontinent.

Slot, K. B., & Berge, E. (2009). Thrombolytic treatment for stroke: Patient preferences for treatment, information, and involvement. *Journal of Stroke and Cerebrovascular Diseases, 18*(1), 17-22.

Appendix K: Definitions

Activity: “any specific action or pursuit” chosen by study participants (http://www.yourdictionary.com/activity

Community reintegration: A process by which individuals who have experienced a stroke are enabled to increase their participation in personal, family, and social roles and thereby improve their quality of life (CSN, 2008, p.6).

Comprehensibility: An individual’s sense of coherence that allows them to make sense of the chaos and ambiguity that disability now imposes upon their lives (Albrecht & Devlieger, 1999).

Disability (Social Model of Disability): Limit or loss of opportunities to take part in community life because of physical and social barriers (Altman, 2001, p. 103).

Disability (WHO-ICF definition): Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (WHO, 2001).

Dilemmatic: The debate or dilemma to questions and choices. It is shaped by prevailing ideology in the social context but also by the nature of individual’s thinking processes (Burr, 2003).

Impairment: problems in body function or structure as a significant deviation or loss (WHO, 1999, p. 16, as cited in Altman, 2001, p. 105)

Manageability: The individual’s perception of sufficient internal and external resources to cope with the problems they encounter (Albrecht & Devlieger, 1999).

Meaningfulness: The capacity to find significance, purpose, and motivation in daily life (Albrecht & Devlieger, 1999).

Paradigm: A set of beliefs or assumptions “we make that serve as touch stones in guiding our thoughts and activities” (Shkedi, 2005, p. 18).

Passing: The term used to describe black people with fair skin who were able to position themselves as white because it offered them the same opportunities as white people (Graham, 1999).

Positioning: The implied position or location occupied by a person in a particular interaction, situation, or discourse (Burr, 2005).

Response shift: The changes in the meaning of one's self-evaluation of quality of life resulting from changes in internal standards, values, or conceptualization (Ahmed, Mayo, Wood-Dauphinee, Hanley, & Cohen, 2005).

Appendix L: Transcription Key

In the interview excerpts, I have used the following abbreviations and conventions:

Mr A:	The participants were assigned a code to protect their identities.
Interviewer:	All interviews were conducted by the author.
[Mr. F’s wife]	Represents names removed to protect identity or a comment I have added to explain the context of the dialogue.
(laughing)	Emotions, noise, or other nonverbal conversational signals that might aid in interpretation of dialogue.
… so.…	Indicates a pause in the conversation.
(pause)	Designates long pause in dialogue.
[.....]	Shows where dialogue has been removed from the interview transcript for brevity.