

**LIFE GOES ON:
AN EXPLORATION INTO THE EXPERIENCE OF COMMUNITY
REINTEGRATION FOR WORKING-AGED PERSONS POST-STROKE**

By

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Abstract

Since 2004, there has been a 12% relative increase in stroke prevalence in the working-aged (18–65 years) population of Ontario. Studies have shown that successful community reintegration is an important indicator of perceived quality of life post-stroke.

The purpose of this interpretive phenomenological study was to explore the lived experience of community reintegration for working-aged persons post-stroke in order to inform the development of appropriate and effective strategies to support their community reintegration and continued stroke recovery.

The essence of the phenomenon of community reintegration for working-aged persons post-stroke emerged as: “Life Goes On: The journey of surviving a stroke in the prime of your life”. Six themes emerged to support this journey of community reintegration after stroke: 1) processing the shock, 2) starting the road to recovery, 3) living with stroke, 4) who am I? 5) carrying-on and 6) transcending the stroke. While participants experienced their personal journey to community reintegration in a unique way, their journey led them to realize that in order to successfully reintegrate back into their community, they needed to adjust, adapt and reach some level of acceptance in order to move on and essentially transcend their stroke

There needs to be a call to action for the delivery of client-centered stroke care. The implications of this study are directed at policy makers, stroke guideline developers, health system planners and stroke care providers in order to develop appropriate and effective strategies and services to support the community reintegration and long term stroke recovery of working-aged persons post-stroke. A client centered approach to stroke care will ensure that the voices of working-aged persons post-stroke are heard and given priority in their rehabilitation and community reintegration planning.

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I would especially like to thank all of the working-aged persons post-stroke who participated in my study. I deeply appreciate their willingness to share their stories with me. This journey of discovery has impacted me both professionally and personally. I truly hope that my thesis facilitates a greater understanding and appreciation of the stroke recovery experience for working-aged persons and helps to advocate for a more client-centered delivery of care.

I owe a debt of gratitude to my family, friends and colleagues for their support and patience throughout this journey. Not only did they demonstrate understanding when I was unavailable, but filled in the gaps and supported me every step of the way. I could not have done this without them. I would like to specifically thank my Mother for always listening to me and for her unconditional support, of both my family and my thesis throughout this process, as well as her help with my editing, which was paramount.

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Table of Contents

Abstract.....	iii
Acknowledgements.....	iv
Table of Contents.....	v
List of Figures.....	vi
List of Appendices.....	vii
CHAPTER ONE: INTRODUCTION.....	1
CHAPTER TWO: LITERATURE REVIEW.....	8
CHAPTER THREE: METHODOLOGY.....	22
CHAPTER FOUR: FINDINGS	42
CHAPTER FIVE: DISCUSSION	81
REFERENCES	110
APPENDICES	122

List of Figures

Figure 1: Key Findings Diagram	45
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List of Appendices

Appendix A: Demographic Information Form.....	122
Appendix B: Participant Study Information Form.....	124
Appendix C: Participant Consent Form.....	126
Appendix D: First Interview Guide	127
Appendix E: First Advanced Interview Guide for Participants.....	131
Appendix F: Final Interview Guide.....	132
Final Advanced Interview Guide for Participants.....	
Appendix G: Analysis Step # 1 – Sample of Holistic Approach	135
Appendix H: “Who Am I?” Exercise.....	136
Appendix I: HHS/FHS REB: Student Research Committee Approval Letter....	138

1**Introduction**

Stroke has significantly impacted the burden of illness for Canadians, contributing to an overall increase in morbidity, mortality and economic costs across the nation (Haydon, Roerecke, Giesbrecht, Rehm, & Kobus-Matthews, 2006; Treger, Shames, Giaquinto, & Ring, 2007). Someone has a stroke every 10 minutes in Canada. There are approximately 300,000 Canadians living with the effects of stroke, and of those almost 88,000 live in Ontario (Kapral et al., 2011). Since 2004, there has been a 12% relative increase in stroke prevalence in the working-aged (18–65 years) population of Ontario (Hall et al., 2011). Although working-aged persons are likely to have lower mortality and less impairment after stroke compared to older persons (>65 years), they will be living longer with the effects of stroke. The psychosocial and economic consequences are likely to be substantial and emphasize the need to address the unique community reintegration needs of this group (Hackett, Glozier, Jan, & Lindley, 2009). Through this study I will seek to understand the lived experience of community reintegration for working-aged persons post-stroke in order to inform the development of appropriate and effective strategies and services to support their community reintegration and long-term stroke recovery.

Community reintegration and stroke

The majority of stroke recovery takes place in the community. The phenomenon of interest for this study is community reintegration and will be defined as “the reorganization of physical, psychological and social characteristics so that an individual can resume well-adjusted living after incapacitating illness or trauma” (Wood-Dauphinee & Williams, 1987, p.493). This definition focuses on “the ability to function, to do what one wants to do or feels one has to do...

Symptoms and disability can be tolerated as long as the individual can accomplish what one wishes to do to his own satisfaction” (Wood-Dauphinee & Williams, 1987, p.493).

Although the majority of persons post-stroke return home from hospital and live in the community, this period of community reintegration is consistently reported to be stressful and challenging (Anderson, 1992; Lindsay et al., 2010; Reed, Wood, Harrington, & Paterson, 2012; Stanton, 2000). The transition back into their community occurs at a time when they have often lost the social, emotional, and practical support provided by an inpatient stroke program (Lindsay et al., 2010). Studies have shown that successful community reintegration, including the ability to return to an acceptable lifestyle and participate in both social and domestic activities are important indicators of patient satisfaction and perceived quality of life post-stroke (Clark & Smith, 1999; Jaracz & Kozubski, 2003; Kim, Warren, Madill, & Hadley, 1999; Mayo, Wood-Dauphinee, Cote, Durcan, & Carlton, 2002; Salter, Teasell, Sanjit, Bhogal, & Foley, 2012). Persons’ post-stroke and their families continue to struggle with community reintegration and find it difficult to regain a good quality of life post-stroke (McKevitt, Redfern, Mold, & Wolfe, 2004; Reed et al., 2012; Bhojal, Teasell, Foley, & Speechley, 2003).

For this reason, there has been an increased interest in measuring outcomes related to community reintegration, participation and quality of life with the stroke population. Most of these outcome measures however, have been developed by researchers and rely on standardized, pre-determined questions, presumed to be important to the person post-stroke (Salter, Hellings, Foley, & Teasell, 2008; Wood, Connelly, & Maly, 2010). As a result of my experience with a pilot randomized controlled trial that evaluated a community based wellness program for persons with stroke, I realized that the results that were generated from the standardized outcome measure that we were using to evaluate community reintegration were not reflective of the

qualitative experiences that the participants were describing. This highlighted a disconnect between the standardized outcome measure and the actual experience of community reintegration for persons post-stroke. The standardized outcome measures that currently exist do not necessarily represent what community reintegration means to the person-post stroke and therefore may not be measuring this construct accurately (Salter et al., 2008; Wood et al., 2010). Through this study, I hope to contribute to the understanding of the lived experience of community reintegration for working-aged persons with stroke, which may help to inform the development of effective measurement strategies as well as the development of appropriate services and supports.

The experiences of working-aged persons post-stroke

Working-aged has been defined, as adults between the ages of 18 and 65 years old (Hall et al., 2012). There has been a 12% relative increase in stroke prevalence in the working-aged group since 2004 (Hall et al., 2011). This emphasizes the need for appropriate and effective stroke services to meet the unique needs of this population (Hall et al., 2012). For the purpose of this study, the focus will be those aged 35-55 years old, in order to assemble a sample that is likely to have a homogeneous life experience.

To date, the recovery experience of working-aged persons post-stroke is not well reported in the literature (Dixon, Thornton, & Young, 2007; Mahon et al., 2012; Stone, 2005a). Working-aged persons post-stroke often come from a different life situation than older persons post-stroke and have a longer time to live with their impairments (Mahon et al., 2012; O'Connor, Cassidy, & Delargy, 2005; Stone, 2005a). While older persons post-stroke may be retired or near retirement after their stroke, this is not necessarily the case for working-aged persons post-stroke (Mahon et al., 2012). The presence of young dependents and the importance of paid employment are

significant realities that working-aged persons post-stroke often need to cope with during their recovery (Dixon et al., 2007; Mahon et al., 2012 Stone, 2005a). The cost of stroke in working-aged persons therefore exceeds that of stroke in older persons due to lost productivity and greater psychosocial complications (Jacobs, Boden-Albala, Lin, & Sacco, 2002; Nayak, Nair, Radhakrishnan, & Sarma, 1997). For this reason, stroke in this population is considered a major socioeconomic issue that needs to be addressed (Bjorkdahl & Sunnerhagen, 2007; Mahon et al., 2012; Mehndiratta, Agarwal, Sen, & Sharma, 2004).

Stroke can result in marital, family and vocational stress for the working-aged adult (Glozier, Hackett, Parag, & Anderson, 2008; Halle, Duhamel, & Le, 2011; Howard, Till, Toole, Matthews, & Truscott, 1985; Teasell, McRae, & Finestone, 2000; Visser-Meiley et al., 2005). Studies have shown that few working-aged persons post-stroke return to previous or any full-time employment one year post-stroke even if physical deficits are minimal (Churchill, 1993; Glozier et al., 2008; Malm et al., 1998). This inability to return to work often results in financial and emotional challenges for the persons post-stroke and their families (Churchill, 1993).

The unique needs of working-aged persons post-stroke tend to be understudied (Dixon et al., 2007). The UK National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2012) suggested that the needs of working-aged adults may not be met by standard stroke services (Daniel, Wolfe, Busch, & McKeivitt, 2009). The Canadian Best Practice Recommendations for Stroke Care (Lindsay et al., 2010) distinguished between the adult and pediatric stroke populations, but did not differentiate between working-aged adults (18-65 years) and older adults (>65 years), even though the two age groups have unique needs related to community reintegration and long term stroke recovery.

There is a gap in the literature related to the experience of community reintegration and working-aged persons. The studies related to community reintegration focus on older adults and the studies related to working-aged persons post-stroke focus on return to work. Little is known about the community reintegration needs of working-aged persons post-stroke.

Research purpose and question

The purpose of this interpretive phenomenological study was to explore the lived experience of community reintegration for working-aged persons post-stroke in order to inform the development of appropriate and effective strategies to support their community reintegration and continued stroke recovery. The central research question was: “What does the experience of community reintegration mean to working-aged individuals post-stroke?”

Research tradition

Phenomenology is essentially the study of lived experience; therefore an interpretive (hermeneutic) phenomenological research approach was the most appropriate approach to use in order to answer this question (Creswell, 2007; van Manen, 1997). An interpretive (hermeneutic) phenomenological approach, informed by the work of Max van Manen (1997) was utilized, following a constructivist/interpretivist paradigm. This paradigm follows a relativist ontology whereby realities are constructed “in the form of multiple, intangible mental constructions, that are socially and experientially based” (Guba & Lincoln, 1994, p.110). From an epistemological standpoint, the constructivist/interpretivist paradigm follows “a transactional and subjectivist assumption that sees knowledge as created in interaction between investigator and respondents” (Guba & Lincoln, 1994, p.111). The philosophical framework for this study was informed by Heidegger’s ontological philosophy, which seeks to “uncover the meaning of what it is to be human...attention becomes focused on the lived experience for it is here where meaning resides”

(Gullickson, 1993, p.1387). The Heideggerian interest in the meanings of ‘being’ are in alignment with my discipline as an occupational therapist.

Using personal experience as a starting point

Van Manen (1997) identified the importance of reflecting on your own personal life experience as an ‘ego-logical’ starting point for phenomenological research. Being aware of my own experience with the phenomenon of interest provided additional meaning and purpose to the process of interpretation. I documented my reflections throughout this study beginning with the journey to my research question:

I had initially intended to conduct a quantitative study using a standardized outcome measure to evaluate community reintegration. Through another research project that I am involved in, developing and evaluating a community based stroke wellness program, I quickly realized the gaps between the information that we were collecting from the outcome measures and the powerful stories that the participants were sharing with me about their experiences. I have always been drawn to the power of the human voice and felt that there was a gap between what people were experiencing and what the data were showing. There is tremendous power in the stories and voices of individuals post-stroke and learning how to evaluate this qualitative data in a rigorous way has become a priority for me. (RF, October 11th, 2011)

I have consistently struggled with how Evidence Based Practice (EBP) is utilized in healthcare. EBP is composed of 3 elements: 1) the best available research evidence; 2) clinical experience and 3) patient values and preferences. However, in my healthcare experience, there is an overwhelming focus on the best available research evidence with a lack of consideration or value given to clinical experience and patient values and preferences – both of which can be best evaluated qualitatively. Has the pendulum swung too far to the quantitative side of things at the expense of what people and clinicians are actually experiencing? There is a real need for more rigorous qualitative research in healthcare to contribute to a more comprehensive implementation of EBP as it was initially defined. (RF, October 12th, 2011)

Not only do I believe that there is a real lack of qualitative research in healthcare in general, and want to support the credibility of this methodology in stroke, but I believe that qualitative methodology, specifically interpretive phenomenology is the best methodology to get at the real meaning or essence of how working-aged people find their way back to their lives again after stroke. (RF, Feb 15th, 2012)

I had both a personal and professional interest in this topic. As an occupational therapist and an educator working with persons post-stroke from two Local Health Integration Networks

(LHINS) in Ontario, I was interested in understanding the lived experience of community reintegration from the perspective of working-aged persons so that we can develop more appropriate, effective and client-centered services for them in the community. As an occupational therapist I was interested in the process of ‘enabling occupation’, in this case with how working-aged persons post-stroke are reintegrating back into their communities. For occupational therapists, the philosophy of client centered practice is carried out through the process of ‘enabling occupation’ (Canadian Association of Occupational Therapists [CAOT], 1997). Occupation can be defined as “all that people need, want, or are obliged to do; what it means to them; and its ever-present potential as an agent of change. It encapsulates doing, being, and becoming” (Wilcock, 2006, p. 343). This notion of people being able to do what they want and need to do, to their level of satisfaction, is integral to successful community reintegration. I wanted to understand how working-aged persons found their way back into their lives after a stroke, what this experience meant to them, and what supports could assist them in successfully reintegrating back into their communities as they continued on their journey of stroke recovery.

Outline of chapters

This thesis consists of five chapters. The present chapter serves as an introduction to the research question and phenomenon of interest, provides a rationale for the study and introduces the research strategy. The second chapter presents the literature review. Chapter Three presents an overview of the methodology utilized to conduct this study. The sampling and recruitment strategy are also reviewed in the third chapter, along with the data collection and data analysis procedures. Key findings are shared in the fourth chapter. Finally, Chapter Five presents a discussion of: the study findings in light of the literature, the implications of the study, and its strengths and limitations and future research directions.

2**Literature Review**

Interpretive phenomenology suggests that a review of the literature occurs twice throughout the research process. The purpose of the initial literature review is pragmatic with the intention of identifying that there is a need for the study (van Manen, 1997). The second literature search occurs during and after the data analyses to identify the relationship between the study's findings and current conceptualizations in the literature. This initial literature review therefore provides an overview of the existing literature related to: 1) the experiences of working-aged persons post-stroke and 2) the experience of community reintegration after stroke. This review demonstrates the gaps in the literature related to the lived experience of community reintegration for working-aged persons post-stroke and will support the need for this study.

Search Strategy

A review of the literature was conducted using PubMed, Medline, Cochrane Collaboration and the Cumulative Index to Nursing & Allied Health Literature (CINAHL) databases for studies published from 1992 to 2013. Search terms included: Stroke (or CVA or cerebrovascular accident), and working-aged adults (or young or middle age or 18-65 years and adult), and community reintegration (or community re-engagement or community integration or participation or community participation or social participation or parenting or employment or work or social life or marriage or relationships). Reference lists of retrieved studies were also reviewed for further relevant studies.

The Experiences of Working-Aged Persons Post-Stroke

Working-aged has been defined, as persons between the years of 18 and 65 years (Hall et al., 2012). Although stroke is frequently considered to affect older persons, approximately one third of strokes occur in people ≤ 65 years (Röding, Glader, Malm, Eriksson, & Lindström, 2009; Stone, 2007; Teasell et al., 2000). There has been a 12% relative increase in the stroke prevalence of the working-aged group of Ontario since 2004 (Hall et al., 2011). This increases the need for a greater understanding of the stroke experience for working-aged persons, in order to provide appropriate and effective stroke services to meet the unique needs of this population (Hall et al., 2012). To date, the viewpoint of working-aged persons post-stroke has not been effectively addressed in the literature (Dixon et al., 2007; Mahon et al., 2012; Stone, 2005a). This study focuses on persons post-stroke, aged 35-55 years, in order to maintain homogeneity of life experience in the sample.

Unique Life Situation of Working-Aged Persons Post-Stroke

Working-aged persons with stroke often come from a different life situation than older persons with stroke and have a longer time to live with their impairments (Mahon et al., 2012; O'Connor et al., 2005; Stone, 2005a). Older persons with stroke may be retired or in a position to consider retirement post-stroke; but this may not apply to working-aged persons with stroke (Mahon et al., 2012). The presence of young dependents and the importance of paid employment are significant realities that working-aged people must deal with during their stroke recovery (Dixon et al., 2007; Mahon et al., 2012 Stone, 2005b).

Stone (2005b) interviewed 22 women, aged 19-58 years, who had sustained a hemorrhagic stroke. Participants indicated that they experienced difficulty coping with society's view of stroke: as a disease of older persons. They felt that they were at a different stage of the life

course. At the time of their stroke, they were either in the paid labour force or planning to join it and they were also either responsible for young children or planning to raise a family. They were in a very different life situation and therefore had very different stroke rehabilitation and recovery goals compared to older persons. The study concluded that stroke rehabilitation strategies were geared to older persons and were not meeting the unique needs of working-aged persons post-stroke.

Several authors have noted a link between the resumption of important life activities and life roles with the self-efficacy and quality of life of working-aged persons after stroke. Dixon et al. (2007) found that persons ≤ 65 years with neurological conditions experienced a greater sense of restriction and decreased participation, expressed as lower self-efficacy, as they adjusted to their altered abilities and attempted to return to their previous productive activities and important life roles than persons > 65 years. Bjorkdahl and Sunnerhagen (2007) similarly reported how the impact of stroke varied according to participants' ability to resume normal activities, which included paid employment and active family involvement. Their study demonstrated a correlation between the resumption of these normal activities and self-reported quality of life.

Mahon et al. (2012), in a review of persons with stroke ≤ 65 years, reported that raising children and paid employment were important realities. This review also suggested that applying findings about older persons post-stroke to working-aged persons post-stroke is not appropriate. Consideration needs to be given to the unique life situation and recovery process of working-aged persons when planning rehabilitation and community reintegration (Teasell et al., 2000).

The Cost of Stroke in Working-Aged Persons

The literature is clear that the cost of stroke in working-aged persons exceeds that of stroke in older persons due to lost productivity and greater psychosocial complications (Brown et al.,

2006; Bjorkdahl & Sunnerhagen, 2007; Jacobs et al., 2002; Nayak et al., 1997). Working-aged persons experience greater life expectancy with their disability and are likely to require continued medical attention as a result of their stroke (Jacobs et al., 2002). In addition, post-stroke depression affects almost half of persons ≤ 65 years post-stroke compared to one third in the general stroke population, which can have significant implications for their stroke rehabilitation and recovery (Eskes et al., 2013; Kappelle et al., 1994; Neau et al., 1998). Stroke in working-aged persons is considered to be a major socioeconomic issue that needs to be addressed (Bjorkdahl & Sunnerhagen, 2007; Mahon et al., 2012; Mehndiratta et al., 2004).

Marital and Family Stress for the Working-Aged Person Post-Stroke

Stroke often results in marital and family stress for the working-aged person post-stroke (Cameron, Cheung, Streiner, Coyte, & Stewart, 2011; Halle et al., 2011; Leys et al., 2002; Röding, Lindström, Malm, & Öhman, 2003; Teasell et al., 2000; Visser-Meily et al., 2005a; Visser-Meily et al., 2005b).

Teasell et al. (2000) found that 38% of person's ≤ 65 years experienced conflict with their spouse post-stroke and that one in seven couples eventually separated. Leys et al. (2002) reported a 7% divorce rate in their sample of persons aged 15 to 45 years post-stroke. Spouses often take on new responsibilities to manage life after their partners' stroke. This can often result in their own needs being sacrificed and contribute to stress, anxiety and difficulty with coping (Teasell et al., 2000; Visser-Meily et al., 2005a).

Stroke also contributes to the family stress of working-aged persons post-stroke (Halle et al., 2011). Younger female caregivers, ≤ 58 years, experienced more emotional distress compared to the older female or male caregivers (Cameron et al., 2011). Spousal strain was frequently related to the children's distress in that they were having difficulty coping with their parents' stroke

(Visser-Meily et al., 2005a). Spousal depression was also correlated with the amount of strain the relationship was experiencing, which significantly impacted on the quality of the marital relationship (Visser-Meily et al., 2005a).

Family strain also occurred when working-aged persons were not able to resume pre-stroke family roles and responsibilities. Women experienced distress regarding their inability to resume roles related to household management and caregiving tasks of their family post-stroke (Röding et al., 2003). Post-stroke fatigue was identified as the primary barrier to the resumption of these roles and activities. Unrealistic expectations were also found to contribute to family strain (Röding et al., 2003). In addition, challenges such as parent-child conflicts, the impact on children as they assume caregiver roles and difficulties with child care negatively affected family dynamics and relationships after stroke (Daniel et al., 2009). The literature has shown that stroke affects all family members including their spouses, children, and often their parents (Visser-Meily et al., 2005b).

Returning to Work after Stroke

The majority of literature regarding working-aged persons post-stroke is related to returning to work. Few working-aged persons post-stroke were able to return to previous or any full-time employment one year post-stroke, even if physical deficits were minimal (Churchill, 1993; Coughlan & Humphreys, 1982; Glozier et al., 2008; Malm et al., 1998). Studies have also investigated the predictors for returning to work post-stroke as well as the connection between work and quality of life and life satisfaction.

Return to work rates.

The literature in the area of returning to work post-stroke has shown that a significant number of working-aged persons are not able to resume paid employment after stroke. Evidence

confirms that between 17-60% of persons return to work post stroke. A survey of 170 spouses in the United Kingdom, found that only 30% of males and 17% of females had returned to paid employment three to eight years post-stroke (Coughlan & Humphreys, 1982). In addition, an American study of 296 persons post-stroke, aged 15-45 years, showed that 61% of participants were unable to return to work due to a residual disability (Kappelle et al., 1994).

Several authors have also noted that several persons post-stroke were unable to return to work despite reported functional recovery (Marini et al., 2001; Varona, Bermejo, Guerra, & Molina, 2004). Furthermore, those that were able to return to work, often required accommodations such as decreased hours to adjust for their stroke (Teasell et al., 2000; Varona et al., 2004; Vestling, Tufvesson, & Iwarsson, 2003). The inability to return to work often resulted in financial and emotional challenges for the persons with stroke and their families as well as decreased life satisfaction (Churchill, 1993; Vestling et al., 2003).

Predictors of return to work.

Several studies have examined the predictors for returning to work post-stroke. Malm et al. (1998) conducted a prospective case series in Sweden, with 24 persons, aged 18 to 44 years investigating the predictive effect of cognitive impairment on functional outcome. They concluded that the primary stroke deficits preventing return to work in their sample included: cognitive deficits, fatigue, anxiety and headache. Only 57% of the participants had returned to full time employment one year after their stroke, several had adjustments made to their previous jobs to accommodate them after the stroke. Roding et al. (2003) conducted a grounded theory study in Sweden, exploring the stroke rehabilitation experience of two women and three men, aged 37 to 54 years. They reported fatigue as the primary barrier to not resuming full time work after stroke.

A retrospective study in Japan for persons ≤ 65 years, post-stroke reported that 58% of participants returned to work and that persons with residual weakness or apraxia together with being blue-collar workers were less likely to return to work, the latter three times less likely compared to white-collar workers (Saeki, Ogata, Okubo, Takahashi, & Hoshuyama, 1995). A further prospective cohort study in Japan examined the association between residual stroke deficits at admission and the rate of return to work in persons ≤ 65 years and found 55% had returned to work at 18 months post-stroke (Saeki & Toyonaga, 2010). Being male, persons with a functional hemiplegic upper-extremity and independence with completing basic activities of daily living were positive predictors for returning to work (Saeki & Toyonaga, 2010).

A prospective longitudinal study in Germany found that 26.7% of persons ($n=70$) aged 30 to 65 years post-stroke returned to work (Gabriele & Renate, 2009). Functional status was the most important predictor of return to work (Gabriele & Renate, 2009). A Swedish survey of 1068 persons post-stroke, 18 to 55 years, reported that 65% of their participants returned to work after their stroke (Lindström, Röding, & Sundelin, 2009). Positive attitudes towards return to work, support from others and higher income jobs were identified as important factors associated with successful return to work (Lindström et al., 2009).

A prospective Swedish study, of 55 persons ≤ 65 years, found that despite functional recovery, only 7% returned to work one year after the stroke and only 20% returned to work after three years. The majority of the sample presented with cognitive dysfunction at one year post-stroke, revealing cognitive functioning as a significant factor for returning to work post-stroke (Hofgren, Björkdahl, Esbjörnsson, & Stibrant-Sunnerhagen, 2007).

The literature revealed a variety of predictors for returning to work after stroke. Several studies revealed decreased return to work rates despite functional independence, which leads the

reader to consider the impact of the more ‘invisible’ stroke deficits such as cognition, perception, mood and fatigue on returning to work post-stroke. Of those who were successful getting back to paid employment, many required accommodations in the form of decreased hours or complexity of tasks. Many working-aged persons are unable to resume full-time employment after their stroke, which may result in marital and family strain as well as decreased life satisfaction (Churchill, 1993; Vestling et al., 2003). Surviving a stroke during the working years of life presents unique challenges related to returning to work as well as marital, family and social roles and responsibilities.

Unique Stroke Rehabilitation Needs of Working-Aged Persons Post-Stroke

The literature described above has revealed the unique life situation and therefore unique stroke rehabilitation and community reintegration needs of working-aged persons post-stroke. The UK National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2012) suggested that the needs of working-aged persons may not be met by standard stroke services (Daniel et al., 2009). They recommended that guideline developers recognize and incorporate the unique needs of the working-aged population into best practice guideline development (Daniel et al., 2009). The Canadian Best Practice Recommendations for Stroke Care (Lindsay et al., 2010) distinguished between adult and pediatric stroke, but they do not differentiate between working-aged persons (18-65 years) and older persons (>65 years), even though the two age groups have unique needs related to community reintegration and long term stroke recovery.

Participants (37-55 years) from a Swedish grounded theory study (n=5) reported feeling “frustrated and invisible due to the fact that the rehabilitation setting does not acknowledge the different needs of young stroke patients compared with older patients” (Roding et al., 2003, p.867). Participants indicated that the stroke rehabilitation environment was geared towards older

persons and lacked age appropriate assessment and therapy approaches. They also reported feeling as though their needs were not being met in the rehabilitation environment and felt detached from the older patients. Participants urged healthcare professionals to gain a better understanding of the unique needs of younger persons post-stroke.

Bendz (2003) conducted a phenomenological study in Sweden, investigating the experience of stroke rehabilitation from the perspectives of 15 persons, ≤ 65 years and their healthcare professionals. The health care professionals tended to ignore key aspects of the young person's stroke experience including: fatigue, fear of relapse and feeling a loss of control. Bendz (2003) suggested that stroke care teams consider the entire person and his or her life situation in order to develop relevant, age appropriate stroke rehabilitation assessment and management plans.

A qualitative study in the United Kingdom, with 37 members of a young stroke survivor group and 12 of their family members, found similar findings to Bendz (2003) and Roding et al. (2003) in that participants did not feel that the rehabilitation they received was sufficient to meet their needs post-stroke and called for an “increased awareness of the existence and impact of stroke in younger people” (Lock, Jordan, Bryan, & Maxim 2005, p. 45).

Working-aged persons have unique needs after stroke. These include relatively high rates of marital problems, family strain, child care issues and difficulty returning to paid employment (Mahon et al., 2012; Teasell et al., 2000). They come from a different life situation than older persons with stroke and have a longer time to live with their impairments (Mahon et al., 2012; O'Connor et al., 2005; Stone, 2005a). Since their life situation and recovery process differ from older persons, consideration should be given to this when planning rehabilitation and community reintegration (Teasell et al., 2000). The majority of the literature related to working-aged

persons post-stroke focuses on returning to work. While this is an important element of community reintegration for some working-aged persons post-stroke it is only one piece of their community reintegration experience. The perspectives of working-aged persons with stroke on their broader community reintegration experience is lacking (Dixon et al., 2007; Mahon et al., 2012; Stone, 2005a). This study aims to contribute to that knowledge gap.

Community Reintegration and Stroke

The literature related to community reintegration after stroke is focused on older adults, however it reveals several important elements that are of relevance to this study and the phenomenon of interest. The majority of stroke recovery takes place in the community. Advances in stroke care have decreased mortality rates and resulted in more persons returning to their homes and communities after their stroke (Heart and Stroke Foundation of Canada, 2006; National Institute of Neurological Disorders and Stroke rt-PA Stroke Study Group, 1995; Wood et al., 2010). The phenomenon of interest for this study is community reintegration and has been defined as “the reorganization of physical, psychological and social characteristics so that an individual can resume well-adjusted living after incapacitating illness or trauma” (Wood-Dauphinee & Williams, 1987, p.493). This definition focuses on “the ability to function, to do what one wants to do or feels one has to do... Symptoms and disability can be tolerated as long as the individual can accomplish what one wishes to do to his own satisfaction” (Wood-Dauphinee & Williams, 1987, p.493). While there has been an increased focus on community reintegration and stroke, the research focus remains on older persons which leaves a dearth of knowledge related to the community reintegration experience of working-aged persons post-stroke.

The Challenges of Community Reintegration

Although the majority of persons with stroke return home from hospital and live in the community, this period of community reintegration is consistently reported to be stressful and challenging (Lindsay et al., 2010; Reed et al., 2012). The transition back into the community occurs at a time when they have often lost the social, emotional, and practical support provided by an inpatient stroke program (Lindsay et al., 2010; Salter et al., 2008). Studies have shown that successful community reintegration, including the ability to return to an acceptable lifestyle, and participate in both social and domestic activities are important indicators of patient satisfaction and perceived quality of life post-stroke (Clark & Smith, 1999; Jaracz & Kozubski, 2003; Kim et al., 1999; Mayo et al., 2002; Salter, Teasell, Sanjit, Bhogal, & Foley, 2012). Persons with stroke, living in the community, and their families continue to struggle with community reintegration and find it difficult to regain a good quality of life post-stroke (McKevitt et al., 2004; Reed et al., 2012; Teasell et al., 2000).

Several authors have investigated the predictors of quality of life for persons living in the community post-stroke. Jaracz and Kozubski (2003) conducted a case control study in Poland, comparing the quality of life of 72 persons of varying ages, 6 months post-stroke with a comparison group of older adults without stroke. They found that persons post-stroke experienced a significantly lower quality of life compared to the control group. Functional status, depression and emotional support were identified as predictors of quality of life. A cross-sectional study in Alberta, with 50 community dwelling older adults, one to three years post-stroke, revealed social support and depression as strong predictors of quality life, more so than functional status (Kim et al., 1999).

Literature in the area of community reintegration post-stroke has also shown a correlation with quality of life and life satisfaction. A phenomenological study in the United Kingdom, with 12 persons of varying ages post-stroke, revealed that participants were often unable to lead active lives and resume pre-stroke roles and responsibilities due to a lack of client-centered community services (Reed et al., 2012). This contributed to a decreased quality of life and revealed the need for a more holistic and client centered approach to supporting community reintegration and long term recovery after stroke. In addition, decreased community participation and decreased life satisfaction was shown in 87% of the participants of a prospective, longitudinal study in Sweden, which investigated the community participation of 161 persons of varying ages, one year post-stroke (Eriksson, Aasnes, Tistad, Guidetti, & von Koch, 2012). A review by Salter et al. (2012) further reported that community reintegration after stroke can be a difficult time for both the person post-stroke and their family due to a loss of previous social roles, social contact, social isolation and poor social integration.

Wood et al. (2010) conducted a longitudinal grounded theory study in Ontario, with 10 participants of varying ages, examining the experience of community reintegration during the first year post-stroke. The study findings revealed dissatisfaction with their community reintegration experience and struggles with depression, social isolation and poor quality of life. After their stroke, participants were most concerned with the social aspect of their recovery, such as resuming roles and responsibilities and reconstructing their self-identity whereas the healthcare professionals focused on the physical aspect of recovery and regaining of independence with basic functional tasks. This disconnect resulted in participants feeling as though their community reintegration and long term stroke recovery goals remained unmet.

Wood et al. (2003) concluded that improving community reintegration after stroke will require better engagement and collaboration between stroke survivors and the healthcare team.

Measuring Community Reintegration

There has been an increased interest in measuring outcomes related to community reintegration, participation and quality of life with the stroke population. However, most of these outcome measures rely on standardized, pre-determined questions, presumed to be important to the person with stroke (Salter et al., 2008; Wood et al., 2010). "Community reintegration is a complex process and cannot be readily measured by quantitative means. Understanding a patient's experience of stroke is essential to develop effective and appropriate strategies to facilitate recovery and promote community reintegration" (Wood et al., 2010, p. 1046). Unfortunately, little is known about what community reintegration means to the person with stroke (Salter et al., 2008; Wood et al., 2010). "At present, service provision is based on the "expert" medical interpretations of recovery; however, this may not be of relevance to the stroke survivor. Provision of services should reflect a more comprehensive understanding of the experience of living with stroke" (Salter et al., 2008, p.600). The standardized outcome measures that currently exist do not necessarily represent what community reintegration means to the person post-stroke and therefore may not be measuring this construct accurately (Salter et al., 2008; Wood et al., 2010). Through this study, I hope to contribute to the understanding of the lived experience of community reintegration for working-aged persons with stroke, which may help to inform the development of effective measurement strategies.

Summary

Although there is a sizeable body of research that has been conducted with stroke, there remains a substantial gap related to the experience of community reintegration and working-aged

persons. The studies related to community reintegration focus on older persons and the studies related to working-aged persons post-stroke focus on return to work. Little is known about the community reintegration needs of working-aged persons with stroke. There is a need to understand the lived experience of community reintegration for working-aged persons with stroke in order to inform the development of appropriate and effective strategies and services to support their community reintegration and long term stroke recovery. This study seeks to contribute to that understanding.

3

Methodology

This chapter presents an overview of the methods used to conduct the study. The research tradition of interpretive (hermeneutic) phenomenology as well as its philosophical underpinnings are reviewed. The sampling and recruitment strategy are described. Max van Manen's (1997) methodological structure which includes the data collection and data analysis procedures are presented. Finally, study rigour and ethical considerations are discussed.

Research Tradition

The purpose of this study was to explore the lived experience of community reintegration for working-aged persons post-stroke. The central research question was: "What does the experience of community reintegration mean to working-aged persons post-stroke?"

Phenomenology aims to understand the meaning of our everyday life. It is essentially the study of lived experience and therefore the most appropriate approach to answer this study's question (Creswell, 2007; van Manen, 1997). An interpretive (hermeneutic) phenomenological approach, informed by the work of Max van Manen (1997), was utilized for this study.

During the evolution of phenomenology as a methodology, two opposing philosophical schools emerged: descriptive and interpretive or hermeneutic phenomenology (Lavery, 2003; Lopez & Willis, 2004; Speziale & Carpenter, 2007). German philosopher, Edmund Husserl (1859-1938), has been referred to as the father of phenomenology and gave rise to the descriptive phenomenological approach. Husserl believed that reality was objective and independent of history and context (Lopez & Willis, 2004). He therefore espoused the notion of bracketing, the process of suspending one's judgment, as necessary to achieve true contact with the essence of a phenomenon. Descriptive phenomenology focuses on seeing things 'as they are' through pure

description of the person's experience and not polluting that meaning with the researcher's perspectives or interpretations (Lavery, 2003; Lopez & Willis, 2004).

Martin Heidegger (1889-1976), also a German philosopher and previous student of Husserl, gave rise to the interpretive or hermeneutic approach to phenomenology (Lavery, 2003). “The word hermeneutic is derived from the name Hermes, a Greek god who was responsible for making clear, or interpreting, messages between gods” (Lopez & Willis, 2004, p.728). Contrary to Husserl, Heidegger’s ontological belief was that reality was inextricably connected to social, cultural and historical contexts (Lavery, 2003; Lopez & Willis, 2004). He therefore did not believe that ‘bracketing’ was possible. Instead of removing the researcher from the situation, interpretive phenomenology sees the researcher as a valuable and necessary contributor to the inquiry process (Lavery, 2003; Lopez & Willis, 2004).

Max van Manen (1997) offered a method to apply interpretive (hermeneutic) phenomenology to human science research. The origin of the word science derives from the Latin term ‘scientia’ which means “to know” (Harper, 2013; van Manen, 1997). Phenomenology explicitly, systematically and critically studies the subject of lived experience and therefore asserts to be a scientific approach (van Manen, 1997). Van Manen’s (1997) method is grounded in the lifeworld, “the world of the natural attitude of everyday life” (p.7) and is deeply rooted in language and philosophy. It is a reflective discipline that seeks to uncover what it means to be human through the processes of reflective awareness and writing. For the purpose of this study, I sought to discover what it means to reintegrate back into the world as a working-aged person after stroke.

Philosophical Framework

A constructivist / interpretivist paradigm informed this approach. From an epistemological standpoint, the constructivist/interpretivist paradigm follows “a transactional and subjectivist assumption that sees knowledge as created in the interaction among investigator and respondents” (Guba & Lincoln, 1994, p.111). This paradigm follows a relativist ontology whereby realities are constructed “in the form of multiple, intangible mental constructions, that are socially and experientially based” (Guba & Lincoln, 1994, p.110). The philosophical framework for this study is informed by Heidegger’s ontological philosophy which seeks to “uncover the meaning of what it is to be human...attention becomes focused on the lived experience for it is here where meaning resides” (Gullickson, 1993, p.1387). A fundamental concept to Heidegger’s ontological philosophy is the meaning of ‘being’. According to Heidegger, phenomenology is the method used to uncover this meaning of ‘being’. Van Manen (1997) further supported this notion, and described hermeneutic phenomenology as “a heuristic of discovery...of the possibilities of being and becoming” (p.xiv).

These meanings of ‘being’ are in alignment with my discipline as an occupational therapist. Occupation has been defined by the Canadian Association of Occupational Therapists (CAOT) as “everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric of their communities (productivity)” (Townsend & Polatajko, 2013, p.377). Ann Wilcock, a researcher in the field of occupational science and therapy, added another dimension to the definition of occupation by including “all that people need, want, or are obliged to do; what it means to them; and its ever-present potential as an agent of change. It encapsulates doing, being, and becoming” (Wilcock, 2006, p. 343). She referred to ‘being’ as “being true to ourselves, to our nature, to our

essence...to ‘be’ in this sense requires that people have time to discover themselves, to think, to reflect and to simply exist ” (Wilcock, 1999, p. 5). ‘Becoming’ adds a future sense to the concept of being. Becoming includes the belief of potential, growth, transformation and self-actualization: every person requires a personal, yet dynamic balance of doing, being and becoming in order to facilitate health and well-being (Wilcock, 1999). The concept of ‘enabling occupation’ was introduced in 1997 by the CAOT and is a core competency of occupational therapists. “Enabling refers to processes of facilitating, guiding, coaching, educating, prompting, listening, reflecting, encouraging, or otherwise collaborating with people so that individuals, groups, agencies, or organizations have the means and opportunity to participate in shaping their own lives” (CAOT, 1997, p. 50). The concepts of ‘being’ and ‘becoming’ are foundational to my beliefs as an occupational therapist and are also key to the interpretive phenomenological approach of this research, which aims to uncover “that which is most essential to being” (van Manen, 1997, p.5).

Setting and Participants

Participants for this study are individuals who sustained a stroke during the working-age (35-55) years of their lives. Initially, recruitment was going to focus on individuals who had participated in the intervention group of a pilot study, a single blinded randomized controlled trial, which evaluated “Fit for Function”, a 12 week community based stroke wellness program at the Les Chater YMCA in Hamilton, Ontario. However, the primary investigator quickly recognized that there were other working-aged persons post-stroke who had not participated in the “Fit for Function” program, but had experiences that would contribute to a deeper understanding of the phenomenon of community reintegration. After consultation with the supervisory committee, it was agreed to extend recruitment beyond the “Fit for Function”

program in order to achieve a more in-depth exploration of community reintegration for working-aged persons post-stroke.

Journal excerpt.

I have had two recent encounters with working-aged stroke survivors who did not participate in Fit for Function but have amazing stories to share...experiences that would really contribute to a deeper understanding of community reintegration. Initially I was thinking that participation in Fit for Function would serve a shared community reintegration experience and contribute to the homogeneity of the sample...but now I am feeling that criterion would be limiting. The overall goal is to get to the essence of this experience...so I have realized that I can't leave people out that I know have rich experiences...I need to talk to my committee about this and hopefully they agree. (RF, April 12th 2013)

Sampling

The study used purposeful criterion sampling as described by Patton (2002): “Purposeful sampling focuses on selecting information-rich cases whose study will illuminate the questions under study” (p.230). Using this strategy, I sought a small homogeneous sample of working-aged persons post-stroke who were living in the community across two Local Health Integration Networks (LHINS) within the Central South Stroke Region. This allowed me to explore the phenomenon of community reintegration in depth within this group (Patton, 2002). Working-aged has been defined by some as adults between the years of 18 and 65 years old (Hall et al., 2012). This study focused on those aged 35-55 years, in order to maintain homogeneity of life experience in the sample. The criterion included men and women of working-age (35 to 55 years) who had sustained a stroke and were living in the community. The sample was balanced for gender in order to fully explore the experiences of each gender group and facilitate comparisons. The following participant demographic variables were also collected: 1) Age; 2) Gender; 3) Time Since Stroke; 4) Education Level; 4) Level of Co-morbidity; 6) Level of Physical Impairment; 7) Employment Status; 8) Marital Status; 9) Status of Dependents; 10) Social Network Status; 11) Socioeconomic Status (see Appendix A for demographic information

form). These variables were collected in order to consider their impact on the findings and contribute to a richer, more comprehensive understanding of the experience of community reintegration for working-aged persons post-stroke.

The sample size for this study was driven primarily by data saturation, defined and operationalized by Morse (1994) as “collecting data until no new information is obtained” (p. 148). It was also guided by Morse’s (1994) recommendation that a phenomenological study include about 6 – 10 participants (Sandelowski, 1995; Speziale & Carpenter, 2007). The sample size was therefore expected to be 6-12 participants, depending on data saturation and resulted in a sample size of 11 participants.

Recruitment

A study information form was sent via email or regular mail to each of the potential participants, requesting their participation in the study (see Appendix B for participant study information form). The study information form included information such as: the purpose of the study, the requirements of the study, information related to confidentiality and voluntary withdrawal as well as the known risks and expected benefits related to participation in the study (Creswell, 2007). The form requested a response from participants via email or telephone to indicate whether they were willing to participate in the study. All non-responses were followed up by a telephone call, in which case the study information form was read as a script over the phone to potential participants. Once participants agreed to enter the study, an interview time was coordinated and a copy of the consent form was taken to the first interview for a face to face consent discussion with the participant. A signed written consent was obtained prior to commencing (see Appendix C for participant consent form). This study took place over a 12 month period from December 2012 to December 2013.

A data management system was set up prior to starting data collection, using N-Vivo 10 computer assisted qualitative data software. Interview and field note data were anonymized, by masking participants' names and removing any identifying information. Paper files were stored in a locked cabinet in a secured office. Electronic files were stored on a password protected computer on a secured network, which could only be accessed by the student investigator. The thesis supervisory committee was provided with access to anonymized transcripts and field notes as required.

Other Data Sources

In hermeneutic phenomenology, data or lived experience descriptions extend beyond the traditional interview material to include other mediums of data such as people's diaries or blogs, autobiographies, films, music and art (van Manen, 1997). During the study, some of the participants referred to Jill Bolte Taylor's (2009) autobiography "My Stroke of Insight: A Brain Scientist's Personal Journey" as a source of information that they found helpful during their recovery process. It became apparent to me that including this autobiography as an additional lived experience description would contribute to a more fulsome understanding of the phenomenon of interest. I then conducted a search for other autobiographies of working-aged persons post-stroke that might be useful to include in the study. This search added two more autobiographies to the data: May Sarton's (1988) "After the Stroke: A Journal" and Bonnie Sherr Klein's (1997) "Slow Dance: A Story of Stroke, Love and Disability". During one of the later interviews, a participant recommended that I look at his online blog, where he had journaled about his recovery experience. This was also added as a final source of data. In summary, this study included for analysis material from 11 interviews, three autobiographies and one online journal.

Max van Manen’s (1997) ‘Methodological Structure of Human Science Research’

Max van Manen’s (1997) methodological structure provided the framework for this study. It is important to note, that while the six research activities are described in a sequential order, they are meant to be a circular process, with a dynamic interplay amongst the activities throughout the research process.

1) ***‘Turning to the nature of the lived experience’.***

This first step includes “turning to a phenomenon which seriously interests us and commits us to the world” (van Manen, 1997, p.30). It involved formulating the research question as well as identifying what vantage point the researcher brought to the study. As an occupational therapist, regional stroke team member, and working-aged adult, I approached the phenomenon of community reintegration with an oriented interest incorporating all of these lenses. It was important that I identified and made explicit any pre-research understandings, biases and assumptions that I brought to the study in order to acknowledge them and their impact on the research process. This was accomplished through the completion of a reflective “Who am I?” exercise at the beginning of the study and then consistent reflexive journaling for the duration of the study and writing period.

“Who am I” exercise excerpts.

The thing that I am most excited about in my study is having the opportunity to actually sit down and spend time with the participants that I will be interviewing to hear their stories and get their perspectives. The healthcare system within which I work is so busy and hectic that rarely do we have the opportunity to spend sufficient time with people to form a real therapeutic rapport and hear their personal stories. Learning about people is something that I get huge satisfaction out of and I am really looking forward to spending time with the participants and hearing about their experiences and perceptions, in detail. (RF, February 12, 2012)

The biggest assumption I am making about what I expect to learn in the study is that there will be gender differences discovered in the meaning of community reintegration with my participants. Initially, my research question would have been more along the lines of: “What are the gender differences in the experience of community reintegration of working-aged persons

post-stroke? I have realized that this assumption is unclear at the present time and that my goal is to discover the meaning of community reintegration, without preconceived assumptions of difference. (RF, February 12, 2012)

2) ‘Investigating experience as we live it’ / Data collection procedures.

This second step was comprised of the data collection process. Van Manen (1997) identified the importance of reflecting on your own personal life experience as an ‘ego-logical’ starting point for phenomenological research. Being aware of my own experience with the phenomenon of interest provided additional meaning and purpose to the process of interpretation.

“Who am I” exercise excerpts.

My most important role in life is that I am a mother to my almost five year old daughter. My ability to care, love, and empathize has been exponentially magnified since having my daughter. Becoming a mother seems to have enhanced my ability to ‘feel’ in general and so I think that this will impact on my research in that I will be very empathetic to my participants. I am also a wife, sister, daughter and granddaughter. Over the past few years, these roles have really taught me a lot about how much I value supportive relationships in my life. I have also learned a lot about being a caregiver. As my grandparents have aged, I have learned through them a lot about dementia and stroke and living with chronic disease, from the family member or caregiver perspective. I have also recently been a patient myself in the hospital. Through these experiences, I have developed opinions and biases related to the service delivery (or sometimes lack thereof) of our healthcare, long term care and community care systems. I am very aware of bringing these perceptions and biases to my research and need to utilize this awareness as I move towards the process of properly integrating these into my research. (RF, February 12, 2012)

A common thread [in all of my life roles] is also my nature to want to help. When someone has a problem, I want to help them solve it. I have come to learn that sometimes people really want and appreciate your assistance, but other times they may just want you to listen. As a mother I have learned that this is a necessary step in teaching my daughter how to solve problems on her own. I need to be aware that I will be interviewing participants to learn more about their experience. I need to be intentional with my attentive listening and not become distracted by my desire to want to help. (RF, February 12, 2012)

Tracing the etymological sources of the phenomenon of interest is another important component of this step. This is done in order to get in touch with its original meaning and any ties to the lived experience. This was accomplished through a search of the etymological origins of the phenomenon of interest: community reintegration. The term community derives from the

Latin terms ‘communitatem’ and ‘communis’ which mean “fellowship, friendly intercourse; courtesy and affability” (Harper, 2013) and “common, public, general, shared by all or many” (Harper, 2013). The term reintegration derives from the Latin term ‘re-+integratus’ which means “to render (something) whole” (Harper, 2013). The etymological sources of community and reintegration are in alignment with the definition of community reintegration that was selected for this study “the reorganization of physical, psychological and social characteristics so that an individual can resume well-adjusted living after incapacitating illness or trauma” (Wood-Dauphinee & Williams, 1987, p.493).

Another important component of this step is searching for idiomatic phrases or common expressions that may be associated with the phenomenon of interest (van Manen, 1997). Common expressions tend to be born out of shared lived experiences and while there were not many idiomatic phrases related to the phenomenon of community reintegration at the outset of the study, several arose during the analysis phase, related to common themes and contributed to a deeper understanding of the phenomenon of interest.

This second step concluded with not only the hermeneutic interviews, but also a review of three autobiographies and one online journal as additional means to obtain an understanding of the experience of community reintegration of working-aged persons post-stroke.

Data collection procedures.

Data were collected by the student investigator only. This study collected data of three different forms: interview material, autobiographies and a participant’s journal. The data collection method of hermeneutic interviewing was used as it was relevant to an interpretive (hermeneutic) phenomenological methodology (Cohen, Kahn, & Steeves, 2000; van Manen, 1997). Participant data were collected through in-depth hermeneutic interviews of

approximately 60-90 minutes in length. The hermeneutic interview is conversational in nature and maintains a strong orientation to the phenomenon of interest. The goal was to facilitate participants' reflections on their experience post-stroke, in order to achieve "a thick description that accurately captures and communicates the meaning of the lived experience....in its fullest and richest complexity" (Cohen et al., 2000, p.72).

"Who Am I" exercise excerpt.

There are two main things that I am afraid of about doing this study, and they both involve the interview process. The first is a fear of not allowing for sufficient silence during the interview. I am not typically comfortable with silence during a conversation, but recognize that this is an important part of the interview process. So, need to ensure that I give the participants time to think and reflect. The second fear is that my quantitative, evidence based, healthcare professional 'hat' will somehow contaminate the qualitative research methodology process by my innate desire to have literature, evidence and theory guiding my practice. In other words, I get comfort out of predictability and control, both of which will be counterproductive to the interpretive phenomenological approach, so I will need to work very hard at keeping that in check. (RF, February 12, 2012)

Van Manen (1997) suggested that there are four fundamental lifeworld existentials that can serve as helpful guides during the interview, reflection and writing processes: lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relation (communality). Lived space includes the physical, cultural, institutional and social environments within which we live. Lived time refers to our temporal way of being in the world, including the dimensions of past, present and future. Lived body relates to the notion that we all experience life through our physical bodies. Lived human relation refers to the relationships and interpersonal space that we share with others. The interview consisted of fundamental questions that correspond to these four lifeworld existentials and facilitate the participants' reflections regarding their experience of community reintegration within the context of having had a stroke during the 'working years' of their life.

I developed the interview guide in collaboration with my thesis supervisory committee (see Appendix D for first interview guide). Participants received a version of the interview guide in advance to allow for preparation and reflection prior to the interview (see Appendix E for first advanced interview guide for participants). Following the first two interviews, I felt that the interview guide was not facilitating the depth of reflection that was needed. Subsequent to reflection and consultation with the supervisory committee, two changes were made to the interview process: 1) The interview guide was modified in an attempt to get at the richness of data required to uncover the essence of the phenomenon of interest and 2) Participants received the entire interview guide in order to prepare for the interview in advance (see Appendix F). Based on listening to the first two interviews, reviewing the transcripts, and feedback from the supervisory committee, I also modified my interviewing style to allow for more silence and reflection time during the interview.

Journal excerpts.

I am disappointed by the instrumental information that was gathered in my first two interviews. No matter how hard I tried to facilitate participant reflection and access the deepest level of their experience...it was unsuccessful. The interview just seemed to lack flow, I spent way too much time talking to them about their stroke experience and not their community reintegration experience and by the time we got around to community reintegration everyone (including me) was tired. The first interviewee actually brought her participant interview guide with her and had written several notes down...I could tell she was thrown off by my questions not matching the ones that she had prepared in advance. Due to the nature of stroke and the potential for residual cognitive deficits...I feel like the participants need to get a copy of the entire interview guide in advance so that they can take the time they need before the interview to reflect and write down notes. Reflecting on the spot is not going to be possible for some of the participants. I really need to connect with my supervisory committee to look at revising the interview guide and participant interview guide before I do anymore interviews. (R.F., Jan 20th 2013)

I had an ‘aha’ moment at my thesis committee meeting today while we were discussing the interviews. At one point I brought up how I wondered if I should consider interviewing the spouses of some of the participants...in particular the wives...because I was worried that the male participants were not going to be as communicative and that there might be an inherent challenge in getting ‘rich and deep’ information from them. One of my committee members made an excellent point in that...it is likely less about the gender of the participants and more

about their comfort with expressing themselves...for example being more introverted or extroverted. She was absolutely right! I was making a biased assumption based on gender, when in reality, as an interviewer I needed to give consideration to how I would approach different participants in order to facilitate their reflection and tap into their insights. It was my responsibility to develop and implement this skill set. Starting with the basics of giving people more time to think and reflect during the interview (RF, March 20th, 2013).

I maintained a reflexive journal and field notes after each interview to capture all observations, thoughts and reflections as well as to record an audit trail. All interviews were digitally recorded and transcribed verbatim by a transcriptionist. Data were collected until data saturation was achieved, as described by Samure and Given (2008) “when information occurs so repeatedly that the student investigator can anticipate it and whereby the collection of more data appears to have no additional interpretive worth” (p.195).

3) ‘*Hermeneutic phenomenological reflection*’ / *Data analysis process.*

This third step consisted of the data analysis process and focused on achieving the essential meaning of the phenomenon of interest. Themes carry a different definition in the interpretive phenomenological approach than they do in some of the other qualitative approaches. Themes are understood as the meaning structures of a lived experience and not the automated application of frequency counts or pre-selected terms, as is found in some approaches. Themes are the tools that reveal the meaning of the experience. Analysis was therefore aimed at determining what the themes were in order to uncover the structures of meaning of the lived experience (van Manen, 1997). Eleven interview transcripts, three autobiographies and one online journal were included in the analysis.

Van Manen (1997) identified three approaches for uncovering the thematic aspects of a phenomenon in text, and they were followed in this study. First is the wholistic or sententious approach. Here, I read and summarized each of the texts as a whole and asked myself “*What sententious phrase captures the fundamental meaning or main significance of the text as a*

whole?” (van Manen, 1997, p.93). I then formulated a phrase that I felt captured the overall meaning of the experience with the phenomenon of interest (van Manen, 1997) (see Appendix G). Second, is the selective approach. Here, I read each of the texts numerous times and asked myself “*What statements seem particularly revealing or essential about the phenomenon or experience being described?*” (van Manen, 1997, p.93). These statements were then highlighted. Third, is the detailed or line-by-line approach. In this approach, I looked at every single sentence of my highlighted text and ask myself “*What does this sentence reveal about the phenomenon or experience being described?*” (van Manen, 1997, p.93).

I then engaged in a search for the etymological origins of emerging themes and significant words in the text. For example, themes related to the recovery process such as “getting back to normal” and “getting back to my old self” appeared as significant in the texts. The term ‘recovery’ derives from the Medieval Latin term ‘recuperare’ which means to “regain health, to come back, to get health back” (Harper, 2013). The meaning of recovery is very much focused on returning to one’s previous state and so was in alignment with what the participants were expressing related to getting back to their old selves and getting back to normal. The term ‘normal’ derives from the Late Latin term ‘normalis’ and means “conforming to common standards, usual state or condition” (Harper, 2013). Similarly, the etymological origin of ‘self’ means “one's own person, same” (Harper, 2013). At some point in their stroke recovery, each participant was very much focused on getting back to his or her old life and self. This process of searching for etymological origins of emerging themes, re-oriented me to the origins and the importance of language during analysis.

I also conducted a search of idiomatic phrases that were associated with emerging themes. For example the majority of the participants in some way described themselves before the stroke

as having a “Type A Personality” or as being an “Energizer Bunny”. The idiomatic phrase, “Type A personality” originated from a theory of personality that was first published in 1959 by two cardiologists, Meyer Friedman and Ray Rosenman when they described this type of personality as a potential risk factor for heart disease. Although this theory was highly controversial in the medical community, it became a part of everyday vocabulary as a way to describe someone’s personality. “People with Type A personalities are often high-achieving ‘workaholics’ who multi-task, push themselves, and hate both delays and ambivalence. They are often rigidly organized, always try to help others, are truthful and take on more than they can handle” (http://en.wikipedia.org/wiki/Type_A_and_Type_B_personality_theory). The idiomatic term “Energizer Bunny” is used to describe a similar type of personality. This mascot for Energizer Inc. was introduced in 1989 to promote the batteries’ ability to continue operating indefinitely (Lynn, 2008). It was a tremendously successful advertising campaign and entered the general lexicon as a term for “anything that continues indefatigably” (<http://encyclopedia.thefreedictionary.com/Energizer+Bunny>). Since common expressions tend to be born out of shared lived experiences, this was extremely insightful with regards to understanding how the participants perceived themselves before their stroke and in some sense how it might shape their recovery and reintegration back into the community.

As was mentioned earlier, the four fundamental lifeworld existentials of lived space, lived body, lived time and lived human relation served as guides to reflection throughout the analysis process. Once themes were identified, I began constructing a diagram of how everything fit together. This diagram became a map that reflected the essence of the experience of community reintegration for working-aged persons post-stroke and will be reviewed in detail during the next

chapter. Collaborative discussions with the thesis supervisory committee served as an additional means to generate deeper understandings and insights (van Manen, 1997).

As has been discussed, the interpretive phenomenological approach to data analysis is inductive in nature. Data analysis occurred concurrently with data collection, beginning with the active listening that took place during the first interview and the field notes and reflections that immediately followed (Ajiawi & Higgs, 2007; Cohen et al., 2000; Morse, 1994). Data were analyzed by the novice primary student investigator, with the analytic steps being checked by more experienced thesis supervisory committee members.

4) *'Hermeneutic phenomenological writing'*

This fourth step involved the writing process, which was also a continuation of the analysis process. The intention of the process of writing was to make visible the participants' perspectives, through capturing their feelings, thoughts and attitudes (van Manen, 1997). Hermeneutic phenomenological writing gives life an objectified presence to our internal thoughts (van Manen, 1997). Writing is considered to be a crucial element of reflective thought and awareness in interpretive phenomenology. When phenomenologist Jean-Paul Sartre became unable to write due to a loss of sight he believed his thinking was significantly impacted as well. "I still think, but because writing has become impossible for me the real activity of thought has in some way been repressed" (as cited in van Manen, 1997, p.126). The writing process for this study was not accomplished in one straightforward session, it involved a complex process of writing and re-writing as the primary investigator reflected on and revisited the findings.

5) *'Maintaining a strong and oriented relation'*

This comprised the fifth step in which I strived to remain focused on the research question at hand throughout the entire research process. "There will be many temptations to get side-

tracked... and indulge in wishy-washy speculations, settle for preconceived opinions... become enchanted with narcissistic reflections or self-indulgent preoccupations, or to fall back onto taxonomic concepts or abstracting theories” (van Manen, 1997, p.33). Maintaining a strong focus and orientation to uncovering the essence of community reintegration for working-aged persons post-stroke was a key element of this study.

6) *‘Balancing the research context by considering parts and whole’.*

Due to the iterative nature of this approach, this sixth and final step required the primary investigator to “constantly measure the overall designs of the study/text, against the significance that the parts must play in the total textual structure” (van Manen, 1997, p.33). It was important that I take breaks from the immersive nature of this approach by stepping back in order to look at the study as a whole. Consultation and collaboration with the supervisory committee further assisted with this. In summary, the six research activities described above guided the methodological structure of this study. They were implemented as a cyclical process, with a dynamic interplay amongst the activities throughout the research process (van Manen, 1997).

Rigour

Rigour will be described according to Lincoln and Guba (1985) in terms of credibility, transferability, confirmability, and dependability. Credibility involves ensuring that the results are clearly reflective of the participants’ perspectives. This was accomplished through member-checking, peer debriefing and the use of direct quotations from the text. Member-checking was completed with four of the eleven participants and was completed through a face-to-face meeting of approximately 30-45 minutes in length. I presented the key findings to each of the four participants and asked for their reflections as well as their feedback related to the findings being reflective of their community reintegration experience. This allowed for opportunities for

clarification as well as provided confirmation of the findings. I also engaged in peer debriefing with my thesis supervisory committee members. This allowed for the peer review of my analytic steps, challenged any biases or pre-understandings that may be unknowingly present in the analysis and ensured that the emergent themes were reflective of participant perspectives. As was mentioned previously, writing is an extension of the data analysis process, and so I included several direct quotations from the data to further support credibility.

Transferability can be described as the extent to which the results of the study can be transferred or generalized to other contexts (Lincoln, & Guba, 1985). Although transferability is not the goal of interpretive phenomenology, the use of thick and rich descriptions of the study context, participant data and themes may be useful to others doing research with people with chronic disease and therefore contributed to this element of the study's rigour.

Confirmability can be described as the extent to which the findings of the study are guided by the participants' lived experience and not the student investigator's pre-understandings or bias (Lincoln, & Guba, 1985). The methodology of this study began with the student investigator explicating assumptions as pre-understandings (van Manen, 1997). Confirmability and dependability were further achieved through the continuous use of reflexive journal writing and an audit trail.

Field notes and N-Vivo 10 computer assisted qualitative data software were used to maintain an audit trail that clearly reflected the entire research process. This audit trail included information regarding any decisions that were made related to the research design, data collection, data management, data analysis and report writing. The reflective journal captured the initial "Who am I?" exercise explicating my assumptions and pre-understandings and was continued with regular entries throughout the research process (see Appendix I). The journal

was an additional means to capture the student investigator's reflections and thoughts to further support the rigour of this study.

Ethical Considerations

A general research application was submitted to the Student Research Committee (SRC) for review by the McMaster Faculty of Health Sciences (FHS) and Hamilton Health Sciences (HHS) Research Ethics Board (REB). REB approval was obtained prior to the start of recruitment.

The participant study information and consent forms were developed in compliance with the FHS/HHS REB requirements. Both forms included information such as: the purpose of the study, information related to confidentiality and voluntary withdrawal as well as the known risks and expected benefits related to participation in the study (Creswell, 2007). They were also in alignment with the FHS/HHS REB requirements to have a readability level of grade 8, with text that is easily understandable and easy to read. Once participants agreed to enter the study, I brought a copy of the consent form to the first interview for a face to face consent discussion with the participant and to obtain signed written consent prior to commencing.

During this discussion, I reviewed all pertinent information related to privacy and confidentiality, as well as collected the participant demographic variables that were described previously. All paper files were locked in a cabinet in a locked institutional office. All interview and field note data were anonymized by removing participant names and removing identifying information. All electronic files were stored on a password protected computer on a secure network.

This interpretive phenomenological study sought an in-depth understanding of the lived experience of community reintegration for working-aged persons with stroke. Ethical considerations concerning the interview, regarded questions which could provoke discomfort or

distress in the participants as they reflected on their stroke experience, stroke recovery journey and perhaps lack of progress. To manage and minimize this risk, I: 1) Clearly articulated these potential risks in the information study form, consent form as well as reviewed during the face to face consent discussion, and 2) Provided the participants with an interview guide in advance to ensure that the participants were aware of the types of questions that were going to be asked during the interview and were able to prepare to answer these types of questions and/or prepare to refuse to answer any of the questions that might provoke too much discomfort or distress (Richards & Schwarz, 2002).

One other potential ethical consideration that I anticipated was that the participants might ask for advice related to systems navigation and access to community resources. In anticipation of this, I developed a resource package that contained any pertinent information related to community supports or resources.

4

Findings

This chapter reviews the key findings that emerged from the data analyses. As was discussed earlier, data for this study included experiential descriptions that were obtained from 11 participants during the hermeneutic interview as well as the utilization of three autobiographies and one online journal as additional resources for experiential material. An outline will be provided regarding the demographic characteristics of the participants as well as the autobiographical material that was included for analysis.

Participant Characteristics

This study included 11 participants. Ages at time of stroke ranged from 34 years to 59 years with a mean age of 46 years. Six of the participants were male. Time since stroke ranged from one to 18 years with a mean time since stroke of six years. Eight of the participants completed post-secondary education, two completed secondary education and one person completed elementary education. There was an overall low level of co-morbidity amongst the participants, according to the Modified Cumulative Illness Rating Scale. All of the participants were ambulatory and able to walk 10 meters independently without a gait aid. Nine participants had good motor return in their affected upper and lower extremities as measured by the Chedoke McMaster Stroke Assessment. At the time of their stroke, ten of the participants were married and one participant was single. Three of the participants divorced their spouses post-stroke. All of the participants had children. Their children's ages at the time of their stroke ranged from newborn to 37 years old, with an average age of 15 years. Four participants had children ≤ 10 years of age, seven participants had children between the ages of 11-20 years and the remaining two participants had children > 20 years of age at the time of their stroke. Prior to their stroke,

ten of the participants were working full-time, with one participant working part-time. Seven of the participants had not returned back to work after their stroke. Four of the participants returned to the same level of work after their stroke. Regarding their financial situation, five of the participants described it as ‘comfortable’, four reported ‘having just enough to get along’, and two described ‘having difficulty making ends meet’.

Autobiographical Material

Three autobiographies and one online journal were also included for analysis. Jill Bolte Taylor (2009) experienced a stroke in 1996, at 37 years of age. She was working at Harvard Medical School as a neuroanatomist at the time of her stroke and has captured her stroke recovery journey in her autobiography “My Stroke of Insight: A Brain Scientist’s Personal Journey”. As was mentioned previously, several of the participants referred to this autobiography as a helpful resource during their own stroke recovery journey and so it was included for analysis. Bonnie Sherr Klein (1997) suffered two major strokes in 1987, while in her mid-forties. She was married with two teenage children, and was working as an award-winning film-maker when she sustained two strokes. Her autobiography, “Slow Dance: A Story of Stroke, Love and Disability” is a comprehensive account of her stroke experience and recovery process, and was also included in the analysis. May Sarton (1988) was 73 years old when she sustained her stroke, she was actively working as a novelist and poet. Her journal “After the Stroke: A Journal” insightfully captures her stroke recovery process and was also included in the analysis. Finally, one of the participants recommended that I review his online journal as an additional source of information regarding his stroke recovery and community reintegration experiences, and so this was included for analysis as well.

Key Findings

The essence of the phenomenon of community reintegration for working-aged persons post-stroke emerged as: “Life Goes On: The journey of surviving a stroke in the prime of your life”. The word ‘journey’ originated in the 13th century and meant "a defined course of traveling; one's path in life" (Harper, 2013). The word ‘survive’ derives from the Latin term ‘supervivere’, which means to "live beyond, live longer than" (Harper, 2013). The essence of community reintegration reflects both of these key concepts.

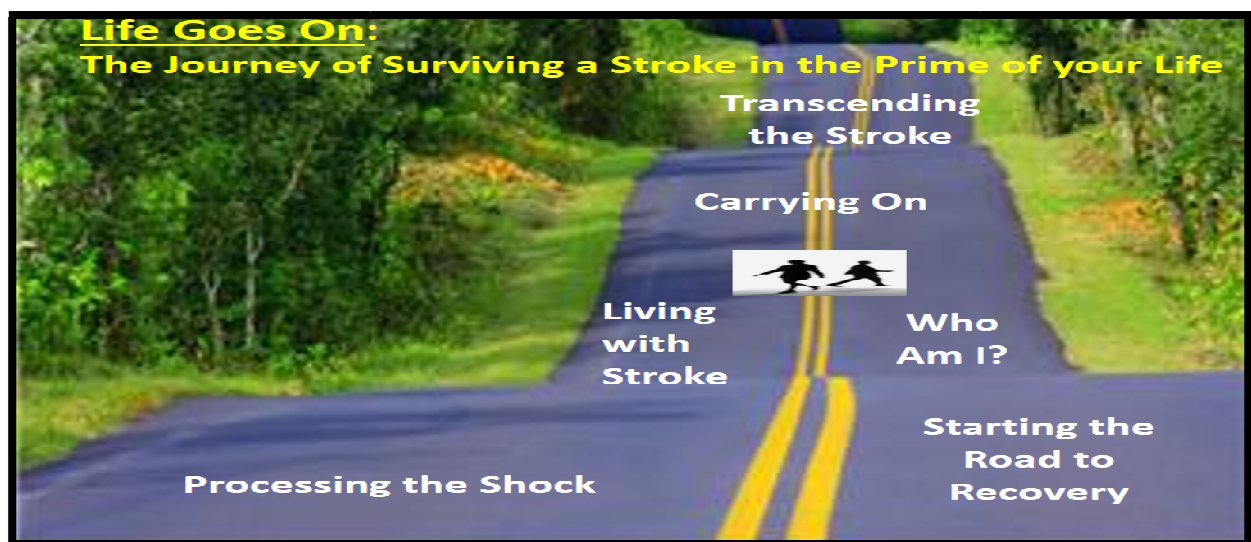
As I interviewed the participants and reviewed their transcripts several themes emerged. Participants described not only surviving the stroke itself, but also spoke of other factors which impacted their recovery and community reintegration after the stroke. They identified the working-aged years of life as 'the prime of life', which is defined as “the time of maturity when power and vigor are greatest” (WordNet® 3.0, 2013). The data revealed that prior to their stroke, the participants had felt they were at the peak of their work, family and social lives. The stroke shook their preconceived assumptions of what life ‘should be like’ during these years. The six themes described below emerged to support their journey of community reintegration after stroke and are reflected in the overarching theme of “Life Goes On”.

“Life Goes On” is a common expression that is “used for encouraging someone who has had a bad experience to continue to live their life” (Macmillan Publisher Limited, 2009-2013). This notion of life going on permeated each of the themes and emerged as significant to the overall essence of the phenomenon of community reintegration. Participants were acutely aware that life was going on around them after their stroke but were faced with the challenge of how their lives would go on. Their journeys led them to realize that in order to successfully reintegrate back into their community, they needed to adjust, adapt and reach some level of acceptance in

order to move on and essentially transcend their stroke. While each participant experienced his/her personal journey to community reintegration in a unique way, similar meaning structures emerged related to this phenomenon and are described in the six themes below.

In the beginning, the participants were faced with “Processing the Shock”. This first theme captured the concept of stroke as an unexpected and traumatic experience. The second theme that emerged was “Starting the Road to Recovery” and reflects the early stages of recovery which often began with an element of being grateful to be alive and then transitioned to a focus on getting back to normal. “Living with Stroke” is the third theme, which addresses the challenges the participants incurred while learning to live with their residual stroke deficits. The fourth theme that emerged was “Who Am I?” and relates to the loss of self-identify due to their changed body and mind after stroke. The fifth theme “Carrying-On” highlights the process of adjusting to a new life which has been changed by the residual deficits of the stroke. The final theme, “Transcending the Stroke”, reflects the experience of each participant as they accept their new circumstances and are able to identify some positive elements of being a stroke survivor.

Figure 1. Key Findings



Six Themes

Theme 1: Processing the shock.

All of the participants described their stroke as a traumatic experience. They were confronted with their own mortality and morbidity at an unexpected time in their lives. The word shock originated in the 16th century as meaning "to come into violent contact, strike against suddenly and violently" (Harper, 2013). Similarly, the participants described their stroke, as a violent, unwelcome and scary event that occurred unexpectedly. They were young and leading active lives and yet suddenly they were faced with their own mortality.

It must have been hours later and my whole face had dropped one side... and then I started crying and I realized this is a stroke but I can't have a stroke, I'm 43. I just didn't think that happened to people that age. (P001)

I think when you are so young having your stroke you have so many more years of life to worry about having another one...so not to say that the worry and the anxiety wouldn't hit an older person, but you know...it's sort of is shocking to happen at such a young age. (P008)

It was shocking for the participants to face their own mortality at such a young age; at a time in their life when they felt strong and assumed they had a healthy and prosperous future ahead. Having a stroke was not something they would have expected, but they were now faced with their own morbidity and disability at a time in their life when they had assumed they would be at their strongest.

Everybody immediately had to realize that it's never going to be the same. And that's pretty huge psychologically...There's a very strong shift in your sense of mortality after something like this. (P004)

Not only was the stroke a shock to the participants and their families but it was also confusing to the medical professionals who took care of them. This was demonstrated through delayed and missed diagnoses of several participants, which was a frightening and frustrating experience for them.

The [EMS] came and said I was having the flu....I remember thinking this isn't the flu...my head was way off to the side, I couldn't even hold it up...then when I got in the ambulance I couldn't swallow, my brain didn't let me swallow and I kept saying I couldn't swallow and they said oh it's because of the oxygen mask, your throat is dry and I couldn't get him to understand that I can't swallow, I'm not able to. (P001)

[The neurologist had decided that he didn't think it was a stroke]...I was [in hospital] for 8 days...then they sent me home...I still couldn't shut my eyes and stand, I would tip over and I was walking with a cane and he said you are better then you were, so everything's good and that was it, just sent me home...It makes me angry to think about that ...the neurologist was just almost flippant, well you're getting better, like that's fine, goodbye. Well, I look at it now ...the neurologist was nice enough but how can you not see this spot on my brain that's damaged, how can you not read that MRI? (P001)

Another participant was teaching her grade three class a lesson when she had her stroke.

That was probably the last time that I spoke that day. [At the hospital] they gave me two CTs, one with a dye, one without. The radiologist was trying to tell [my neurologist] that it was a picture of a stroke...[she didn't agree]...she said ...I believe that it's inflammation causing the same dot...They didn't give me the clot buster, they didn't diagnose a stroke... [I was sent home]... I sat on that couch [at home] just staring out the window all the time because that's all I could really do for a while... [six months later I was sent to] a [stroke] neurologist....and he knew right away ... [that I'd had] a stroke...I remember feeling upset because he said, quicker is better in treating strokes. (P004)

Another common element offered by the participants, was an explanation regarding the reason for their stroke. In an attempt to make sense out of their stroke experience, participants attributed risk factors such as stress or unhealthy eating as the cause of the stroke. The word attribute derived from the Latin 'attributus' in the late 14th century and means "assign, bestow" (Harper, 2013). The reasons that participants attributed as the cause of their stroke also held them responsible for their stroke, due to behaviours such as poor eating or leading too stressful a lifestyle. One participant had recently returned from a trip with his friends and attributed his stroke to excessive eating and drinking during his time away.

[I] think that a lot of [my] stroke problems came from putting on weight too quickly, eating fattier foods which I guess got into the arteries here, cut the oxygen to my brain which in turn gives me a stroke....I was at the Masters [golf tournament] the week before the stroke and I ate a lot of steaks, I drank a lot of beer, a lot of fatty foods. (P003)

Several participants attributed their hectic and stressful lifestyles as the cause of their stroke:

I think I had way too much stress and not enough sleep and exercise. (P009)

Since we didn't know the cause of my stroke, I assumed it was stress. The idea that I'd somehow brought it on myself was hard to shake. Maybe I'd been living too long in the fast lane and was now paying the price for trying to have it all. (Bonnie Sherr Klein [BSK], 1997, p.41)

[Shortly before the stroke] I told [my friend] I wanted help to slow down, find balance, and start living in the present moment...Lying in the hospital bed, I ...wondered, could this stroke be what I needed to make changes in my life? ...Maybe this experience was a message from my body: its way of telling me something important. I remember joking that my body had to shout really loud to get my attention. (BSK, 1997, p.44)

I used to say to people [that] the stroke for me was [that] I was taking myself way too seriously. I was putting way too much of myself into my job...and God just picked me up and shook me, shook my head and said okay here, try it again. (P004)

In summary, processing the shock of a stroke event at a time in their lives when they felt they had a vibrant future ahead, the participants were confronted with their own mortality, morbidity and a life ahead of unknown disability. An attempt to make sense of such a traumatic, life changing event led them to seek a cause: to attribute something in their lifestyle which would have precipitated their stroke. “Processing the Shock” represents the beginning of their journey to surviving a stroke in the prime of their life.

Theme 2: Starting the road to recovery.

After processing the initial shock of having a stroke and facing their own mortality, participants described feeling grateful to be alive and hoped for a full recovery. This early phase of recovery was very much focused on getting back to normal. One participant described feeling lucky to be alive:

To be able to walk, be able to go get a haircut or be able to go back to work...We are very, very lucky. We feel lucky because we've seen the other end of it. (P003)

This gratitude was followed by a fierce commitment to getting back to normal and resuming their old lives. Participants were hopeful that they would fully recover from the stroke and regain their former unimpaired selves.

I wanted to...get back to normal because I was only 49 and because I was so healthy and active prior to the stroke...I wanted to get back to that person. (P008)

I just knew I was going to get through this. I was going to walk again. I was going to... come hell or high water I was going to get myself out of this wheelchair. I was going to be a mom to my boys. I was going to be able to get my life back to what it was. (P010)

The hospital environment for most participants was not ideal. They were surrounded by predominantly very sick, disabled, older people at a time when they needed a more cheerful, hopeful surrounding.

I was really in an area [of the hospital] where most of the people on that floor were seniors...that were waiting to go to a nursing home. (P008)

[Looking at the other patients, I thought]...we have nothing in common. This is only a passing phase for me: I'm going to be healthy and 'normal' again soon. (BSK, 1997, p.192)

Participants also revealed feeling misunderstood by the medical teams. They felt that their healthcare professionals did not seem to appreciate that they came from a different life situation than the older patients in the hospital. They were coming from a life situation where they were still actively working and parenting and needed to recover sufficiently to get back to that type of lifestyle. They also felt that their brains and bodies were young and primed to recover. They were going into the stroke with strong minds and bodies and were dedicated to working hard on their rehabilitation. Participants described feeling as though they were part of a cookie cutter approach that did not meet their needs. They did not feel as though they were receiving client-centered care. As a result, several participants experienced frustration and felt as though they were working “against” a hospital system that did not seem to understand them. In this sense, they felt responsible for their own recovery, as if it were up to them to lobby the medical teams

for an appropriate recovery plan. They felt as though they had to advocate for themselves and prove the medical teams wrong.

One participant described her experience of feeling as though the medical team was working against her recovery, not supporting it.

I was going to do whatever was necessary to get better. To work hard, to figure out what was working for me, what wasn't working, and not taking pressure from the medical team...[who thought that I was] not accepting [that I'd] had a stroke...How many times I heard that word plateau, my God... I heard ...you are not accepting it, you reached a plateau and might not get any better. Certain people were just trying to send [me] so much negative feelings and if I wasn't as strong as I was I would have sunk. I would have said, okay you're right... [and]....I would not be where I am today....Luckily...I'm a strong [and determined] person... with a loving and supportive family. (P010)

Another participant described his negative experience at a family meeting, where he felt as though the physicians didn't understand him or his abilities. He felt as though he was receiving a 'cookie cutter' spiel that was geared for older adults. This experience was more damaging than helpful.

When we went to this [family] meeting ... them doctors are so out to lunch...He told me that I'll never do nothing again and basically I was a vegetable...the one doctor told me you can't walk on grass again... you'll do no gardening, you won't be able to do the lawn no more. [I thought] well... I just finished cutting the grass before I got there. Ha ... I said to my wife when we walked out of there... I'm never going back to see that guy again...I didn't trust him...they make it sound like [your] life is over....and at first I believed him. (P007)

Everybody gets the same spiel in the hospital... I understand strokes happen a lot to older people [but] that's the way they treat everybody...When I was listening to him, [tell me all of the things that I] won't be able to do any [more]...I thought it was just a bunch of crap because I do 'do' things...They walk all over you it seems...the doctors the way they tell you things...and I believed them at first. (P007)

In this case, the family meeting seems to have been dominated by an institutional 'risk management' lens versus a more client centered 'managed risk taking' lens and did not meet this participant's needs.

One of the autobiographical descriptions also speaks to the importance of client-centered practice and empowering patients in their recovery.

We need health professionals to listen well, to encourage our hope, and to join us as allies...Together we need to heal our health-care and rehabilitation systems, to promote a vision motivated not by the bottom line, but by a collective commitment to the best care for all. (BSK, 1997, p.312)

As time passed, participants described the experience of beginning to realize that their recovery was going to be a slow process. Since most of the participants were accustomed to very active and busy lifestyles before the stroke, this became a new and very difficult reality for both themselves and their families to accept.

There was a frustration that set in...[seeing how slow the recovery was]...because I was beginning to understand that...this is going to be a long process...and for a 41 year old person, slow is not a word...It's not a word that we embrace...snail's pace is... not in your vocabulary. So, understanding slow was like a slap in the face...so that was hard for me...it was difficult for my family too. (P005)

Another participant talked about having to manage her expectations related to her recovery and adjusted her goal-setting as she began to realize that her recovery was going to be slower than she had anticipated.

I had decided that I was going to be out of [the hospital] by the end of January... [and that]things were going to be back to normal and I was going to be home. Ha, by the end of January I was still learning how to transfer myself from the wheelchair to the toilet. I was still trying to deal with brushing my teeth...I would be wheeling myself to the bathroom and looking in that mirror and crying...and then at the end of January [I gave myself a reality check] ...this isn't happening the way that I wanted it to, so I have to change my way of thinking. I have to change my goal...This was tough for me to accept. (P010)

Another participant revealed how she needed to change her outlook on life in order to feel good about the recovery process.

[I learned that recovery] was slow and it was up to me...I needed to be patient with myself which...was very humbling to accept that everything I set my hand to didn't need to be perfect.(P004)

Participants also began to realize that although they were holding on to the past and focused on getting back to normal, the stroke had changed them forever. Their desire to fully recover and resume their old lifestyles was becoming less of a reality. However, they still had responsibilities in their roles as parents, spouses and employees so there was fear and sadness associated with the notion of not being able to get back to normal.

I wanted only to return to normal, to be ‘the old Bonnie’ again. I couldn’t conceive of coming to terms with being disabled, let alone a world where differences could be accepted and accommodated as a right, not a burden.” (BSK, 1997, p.178)

The adjustment of goals and the imposed change to the vision the participants had for their future was very discouraging and difficult to navigate. One participant described how this was not what he had expected nor wanted for himself and his family:

I had my stroke [right before] our tenth wedding anniversary... [which was] kind of a big deal to me... my wife was pregnant....It was kind of depressing...my wife had the baby while I was in rehab....So I just got in my wheelchair and went up the elevator and sat right in with my wife when she had her C Section. Not the exact way I wanted to remember that...Not for her either, you know? (P011)

Another participant described the devastation she experienced when both she and her children realized for the first time that she was unable to be the mom she used to be.

It was in the winter time and [my son] was two and they were getting ready to leave [the hospital]...and [he] looked up at me to help him with his little winter coat, to do up the zipper. Oh my God, that broke my friggin’ heart because of course I couldn’t because I only had my left hand and [he] is looking up at me and of course he’s now realizing that I’m paralyzed and what I can’t do anymore. God that broke my heart. (P010)

“Starting the Road to Recovery” begins with gratitude for being alive and hope for a full recovery. Then over time, most participants begin to realize that although they have been focused on getting back to normal, this may not be their new reality.

Theme 3: Living with stroke.

Living with stroke would not be a smooth and uneventful process. Participants experienced many challenges along the way and how they dealt with them was a determining factor to their road to recovery. During this time in their journey they came to understand that they would have residual deficits from the stroke and would not likely reclaim their former unimpaired selves. This realization that they may not regain a smoothly functioning mind and body impacted on the relationship that they had between their bodies and their senses of self, and often resulted in a loss of self-esteem, self-confidence and self-identity.

I had a stroke, [but] I'm still me...You are realizing subconsciously that you are just basically not the same. You are the same person but you are a changed person. (P004)

Participants began to grieve the loss of their former abilities. They began to experience what life was going to be like living with stroke. One participant described the sadness he experienced when he realized how he and his life had changed.

I was a bit depressed at first...for the loss of my arm and the loss of my leg and... I'm not as ... go, go as I used to be ... I was a ... two stairs at a time type of guy...But now I'm a one barely at a time...[So it slows you down]...and that bothers me....I'm [also] not... the funny guy that I used to be I have a lot of pain [now]...on my left side...and you don't really feel like making jokes when you are in pain...So ... even though I try to be kind of funny sometimes... I'm not as funny as I used to be....The worst part is that I've still got no movement whatsoever in my arm... [so I can't do] things around the house like [I used to]. (P011)

For the participants who experienced predominantly physical deficits such as hemiplegia, sensory loss and decreased balance, the challenges were evident.

[The] hardest part for me probably was living without the use of my arm and my proper use of my leg ...because I was such a ... hands on guy, I could do everything myself. (P011)

Use of my hand is probably the biggest thing that bothers me...before I do anything I [have] to think about it and make sure I [have] the right way of doing [it]...because I don't want to hurt myself...because my wife would get mad at me and might say...you can't do that. (P007)

My kids were actually standing behind me for the first few days...Just to make sure I didn't fall or anything. (P008)

Further challenges were described by participants who experienced predominantly invisible deficits such as fatigue, anxiety and changes with cognition and perception. These deficits impacted the participants' ability to engage in meaningful activities, participate in the community and resume important life roles such as parenting and returning to work. For some of the participants who experienced mostly 'invisible' deficits, they described the struggle of living with increased anxiety and fears and being misunderstood by their families and friends.

One participant described the challenges that post-stroke anxiety imposed on his life.

Every once in a while a little bit of anxiety would kind of creep in...that became the challenge for me...I would be sitting in the office or standing around the coffee machine...and all of a sudden I would get this feeling that I'm going to have another stroke and it's going to happen right here....and I would picture what would happen. You know...one of the ladies from the office would call 911... all these things go through your head...I would say, after the initial recovery of the stroke the anxiety issue was probably the most difficult for me...[it] got so bad I actually went back to [the hospital] one morning, my wife drove me...and I went through all the tests again and they confirmed no you are not having another stroke ... that's when I did get anxiety pills. (P008)

Other participants also described feeling as though no one, from their own family to the community at large, understood that they continued to experience residual but invisible deficits. They expressed feeling as though people expected more from them than they could achieve, which further impacted their self-esteem. They went on to suggest that having some type of visible indicator that they were stroke survivors, would serve as a helpful visual tool to facilitate compassion, support and empathy from others as they tried to reintegrate back into their communities.

...Young Stroke Survivors we all agree that we are going to go get handicap tattoos on our forehead...Because people look at us and they don't think there is [anything]wrong. (P005)

I never wanted sympathy and only wanted to get better but now I see that I may not receive the same compassion I once did...hence me thinking it's time to get the cane back. It's not

that I need it but it would be an indication that something is not right and maybe others would not expect more from me than what I demand and hope for from myself. (Blog, Jan 31st 2011).

It's hard meeting people that I know and they're [like]...you're not back at work? Everyone just assumes because there's no physical deficit that I'm fine. (P001)

One participant spoke of a 'new generation' of stroke survivors, those who had sustained their stroke during the era of the clot busting drug, intravenous Alteplase or tPA. She described how she felt the administration of tPA had spared her the residual physical deficits of stroke, but had left her with 'invisible deficits'.

We are the new generation of stroke survivors that look well because of the tPA but we are just as handicapped as the guy with the quad cane [or] ... the wheelchair, but in different ways... [People] in the community [don't understand that]...[they] don't make the connection ... so everyone responds to me as though I'm a normal thinking, processing, evaluating, hearing person but in fact I am not. (P005)

Several accounts described incapacitating fatigue as a significant reality of their post-stroke life, which impacted on their ability to engage in meaningful activities and life roles.

What oceans of energy I need to have! It astonishes me now even to imagine what I used to be able to do" (May Sarton [MS], 1988, p.47)... Daily chores seemed insuperable. Making my bed left me so exhausted that I lay down on it once for an hour. (MS, 1988, p.29)... Everything that I want to do takes energy that I do not have, so looking at the garden and its needs is a kind of torture. (MS, 1988, p.45)

I don't know if I can adequately describe the fatigue: it was profound, blinding, literally unspeakable. When fatigue hit I could no longer form words in my mind or my mouth. I stammered and my tongue got in the way. All my new skills deserted me and I cried for my bed. (BSK, 1997, p.164)

I'm so tired of being tired. Every little activity is big...like taking a shower. You shower before doing something right? ...But no, for me a shower requires going back to bed afterwards to recuperate. (BSK, 1997, p.226)

[Mental fatigue] becomes physically fatiguing because your awake hours are nothing but always continually figuring things out. (P004)

Participants with invisible deficits wondered if community reintegration would have been easier if they had sustained physical deficits instead. Conversely those that experienced

predominantly physical deficits speculated that life after stroke might have been easier for them if they had been spared their motor impairments and sustained more invisible deficits.

It's awful to say but sometimes I wish it was just physical with me, but then that would be a whole other gamete of problems. (P001)

[This stroke survivor] said he'll never work again... but [it] didn't look like there was [anything] wrong with him, I wish I looked like him. (P007)

I look at other people walking down the street ...and I wish I was like them...they've got everything going for them...They can walk faster, they can run down the street, they can do a lot more than I can do.(P003)

There is an element of the 'grass is always greener' in this sense. 'The grass is always greener on the other side (of the fence)' is an idiomatic phrase that means, "People always think they would be happier in a different set of circumstances. (Usually implies that the other circumstances really are not any better)" (McGraw-Hill Companies, Inc., 2002). Participants expressed having these thoughts as they lived with the effects of their stroke and struggled to make sense of their new life circumstances.

Participants also described how much of their previous life they took for granted: the automaticity and reflexivity of certain tasks like parenting and going off to work each day. Since the stroke, they described the need to consciously think everything through; how nothing could be taken for granted. For one participant this included the basic task of swallowing.

I have to be careful when I'm eating or drinking to make sure that I focus on swallowing or I've had many choking episodes where you think it's going to be game over...[so] you really have to have a concentrated focus now. It's not automatic anymore. Nothing seems to be automatic... [there are] so many things we took for granted as being automatic.. (P009)

For other participants it included just trying to get up and get going in the morning.

My brain makes it hard for me to get up, think, [and] move...because now those things are no longer classified as reflex. They are actual tasks [that need] to be considered what's to be done first, second and third...Breathing is not reflex [anymore], it's a task. (P005)

Showering was not automatic, you know, where you could just do what you normally do in the shower... it was a bit of a struggle. (P008)

Regardless of the type of residual deficits, all of the participants expressed the challenge of completing the most basic activities of daily living, post-stroke. They revealed again the shock and frustration of not being able to do what they used to do and how life post-stroke did not fit with the vision they had for themselves in the prime of their life.

One participant reflected on the level of appreciation he acquired for the things in life he used to take for granted.

Naturally many stressful things can evolve out of having a stroke, loss of abilities, job, house, car, marriage and finances to name a few. There's an old saying [that] you don't know what you have until it's gone. (Blog, Jan. 29th 2011)

Being unable to drive after their stroke had significant implications on the participants' community mobility, their ability to successfully reintegrate back into their communities and for some, on their ability to return to paid employment.

They took my [driver's] license away for a year and a half...so I had to learn how to use our bus system...I didn't even know how much a bus cost to get on, that's how bad it was. But I had to learn... Then I got a job in Toronto...[so I had to learn how] to take the GO Train and then [the subway]... I had never been underground in Toronto in their transit system... and I wasn't sure how to do this...[but] I didn't have a license ...so I had to.(P003)

Being able to resume important life roles such as parenting were suddenly challenged by the residual deficits of their strokes, roles they took for granted just weeks before. One participant went home from hospital to a newborn daughter. He had a severe residual left side hemiplegia and although he described a magnitude of challenges that he encountered in relation to his ability to father, he also shared one of his particularly triumphant experiences.

For the first few months I was home we had a neighbour that babysat [my daughter]... because she was a baby still and needed her diapers changed and things ... that I really couldn't do or think I could do anyway. Until... one day... my wife wanted to go to the store ...she said do you think I could leave [our daughter] with you? ...I said, as long as she doesn't have to have her diaper changed... that would be great.....my wife wasn't gone... out

of here two minutes and ... she needed her diaper changed. Somehow I got her up to her bedroom ... I got her on the change table; she lifted her legs straight up in the air ...I couldn't believe it. It's like she knew [I needed help]...it was crazy...and I managed [to change her diaper]...[when] my wife came home, she was so proud of me, she couldn't believe that I could change a diaper...I was so proud of myself...I was just about twisting myself trying to pat myself on the back. (P011)

Another participant had three young children under the age of five at the time of her stroke.

Her stroke recovery was full of challenges as she resumed her role as mother; however, she described how her children were also her source of inspiration.

When I used to go home on weekends, my youngest [child] was still in diapers and I couldn't change his diaper, that was a real struggle. There was just so many things I couldn't do. And ...there was no way that I was going to accept that that was what my life was. (P010)

My kids were everything to me. I would not be where I am today had it not been for my kids. (P010)

Resuming the role of mothering her teenage children presented challenges for one participant. Her stroke resulted in predominantly 'invisible' deficits, which made it hard for her girls to realize that the stroke had affected her.

[They] still expect old mom... I remember my daughter coming home from school ... [and wanting advice]...after she described the situation... she was like, so what do you think mom? As usual she was expecting an array of solutions that she could pick from, that she knew were going to be right. [When] I said...can I let you know what I think tomorrow? ...she was stunned...she said, no mom, come on...you do this, you do this quickly, come on... tomorrow is too long... And so I realized that she did not see me...She saw this body that resembled the old person, it looked the same. She could not see my injury...That's been the tenure of our relationship, with both my daughters. They don't see my injury and they don't understand it. (P005)

Work was another task that had been taken for granted, sometimes even a source of complaint. But now post stroke, returning to work became a meaningful milestone. For some participants, their deficits impacted on their ability to pursue employment in the way they had, prior to their stroke. One participant related how much his work meant to him.

[Work meant] everything to me...sometimes it was more important than my family. (P003)

But for all of the participants, not being able to return to work had significant impact on their sense of productivity which in turn impacted on their sense of self-worth, self-confidence and self-identity. One participant described how his employer misled him and gave him false hope for a return to the workplace where he had been very successful. This was an extremely upsetting experience for him.

After I had my stroke, [my boss] didn't want me back...[they]kept pretending like they wanted me back...[saying things like] we are saving your office for you... we can hardly wait until you come back...Then one day I called and [they]...made up some excuse about insurance or something like that and so basically what they were trying to tell me is they really didn't want me back...So, I was kind of broken hearted...I worked there for six years. I did a heck of a job for the guy and made him tons of money and ... just because something rotten happened to me he didn't want me back...work was everything to me. (P011)

Another participant described how he knew that he would be unable to return to his old job, due to its physical demands and his residual hemiplegia and motor impairments. However, he described how being productive and finding a job, would be important to his successful community reintegration. He also stated that he had to officially retire from his position in order to be eligible for the medical coverage that he needed for his stroke prevention medications.

[I feel] terrible [about not going back to work]...I want to do something...I can't go back [to my old job]...I've had to retire...because I needed my medical [coverage]...so I can't go back there...as much as I would like to, I can't. [I want to find a job though]... I don't really care [what it is]...if I can get a job with minimum wage, I don't care...[I'd do] anything. (P007)

Feelings of inadequacy and a lack of confidence in his ability to contribute were described by another participant.

I do not feel the competency that I had [before the stroke]. When I worked I felt very competent with everything that I was doing ...and now it just seems like that's all gone...I'm not sure if most stroke survivors would say that but it seems like it not only strips you of your abilities, it strips you of your confidence...and that has been ... a big omission from my life... that confidence to do stuff. (P009)

Not being able to return to work also had financial implications for the participants and often added strain to their family incomes and lifestyles.

I think the hardest part...is accepting that I will never work at a job that will pay me to support myself. The fatigue prevents manual labour... The lack of mental skills...keeps me away from an office job...The fatigue [also] prevents me from holding an office job that's even part time...So the hardest thing for me at my age was to accept ... the idea that I'll never work again at something that will pay me to support myself and my kids.(P005)

Living with Stroke and the residual stroke deficits was life-changing for the participants and their families. It was not only a period of grieving the loss of their former unimpaired selves, but a realization of what post-stroke life was going to be like, not only for themselves, but their families as well. Participants began to realize that not only was life after stroke going to be different, but that it was going to be difficult as well. They described their struggles with completing basic activities of daily living, engaging in meaningful activities such as paid employment and resuming important life roles, all of which had significant impact on their self-worth, self-confidence and self-identity.

Theme 4: Who Am I?

Participants revealed the impact that their deficits had on their self-esteem, self-confidence and self-identity. They also described how their loss of normalcy and inability to resume certain meaningful activities and life roles resulted in an erosion of their sense of self. A mother unable to care for her children, an artist unable to draw or paint, an educator unable to read, a poet unable to write, a hockey coach unable to skate were once unimaginable but now a reality. Participants revealed feeling scared, deprived and confused regarding their self-identities as the roles and activities that once defined them had become challenged by their inability to participate fully in them. This was the beginning of their reflective journey of self-evaluation.

One of the participants was an educator and described teaching as her purpose in life. After her stroke she was unable to read. Reading had been something that was important to her since her childhood and it was an integral part of how she defined herself.

I couldn't read a thing ...I used to be so smart...I mean, an educator trying to read a book is a big deal when they can't do it, right? ...I've become like the Scarecrow in the Wizard of Oz. I won't try to manage things because I can't think. (P004)

Since I was a little girl [reading] has been such a huge part of my life... it made me feel good and I could envision the story and I've been robbed of that...which is sad...that part is missing. (P004)

The same participant was also an artist. The location of her stroke took away her ability to visualize and therefore took away her ability to do her art, which was an important element of her personal identity.

[The stroke] really affected my ...mind's eye...a lot of art is...seeing something in your mind and putting it on paper...[I've lost that]...I can't see anything anymore...so my art kind of [disappeared]...art is what made me special...what made me, me.....it was a very humbling experience...it really changed me. (P004)

Another participant described his passion for hockey. He not only played the sport for most of his life, but he'd coached for 13 years before his stroke. His residual impairments prevented him from playing and resuming his role as the head coach of his son's hockey team.

I coached hockey for... years, so people have known me...as a very competent, athletic, capable person...now they see me and I've been asked...why aren't you on the ice?...[my] balance [and] vision problems [are] very invisible...those invisible deficits are actually a bit of a detriment to us because we are being expected or looked at like, you should be doing this or that...We want to do it more than any of them want us to do it....It's really hard when it's thrown at us, and it's like why aren't you doing that? ...it's like well I wish I could, you know, I just can't... it's very hard for me to go back into the hockey world and stand behind the bench and stand in the dressing room I...still have a hard time with that....you don't have the same self-esteem. (P009)

One of the autobiographical authors was a writer and a poet. Her inability to write after her stroke had a monumental impact on her self-identify. Writing was what made her complete, it

was how she defined herself. The inability to write and explore her thoughts left her anguished, empty and unfulfilled.

...The smallest effort, mental or physical, exhausts, [and] I feel so deprived of my 'self' being unable to write, cut off since January from all that I mean about my life. (MS, 1988, p.15).

The absence of psychic energy is staggering. I realize how much it takes to write one line. And I have tried in vain, over and over to write a poem....and wept with frustration because poetry is not in me. Will it ever come back? Shall I ever feel whole again? (MS, 1988, p.24)

I have not been able to listen to music at all...perhaps because it has been closely connected with poetry. I don't dare, for fear of breaking into pieces. (MS, 1988, p.32)

Participants also revealed the impact that their deficits had on their relationships with their family and friends. As they adjusted to life after stroke, they had a renewed awareness of the significant people around them and the impact their stroke had on their relationships. Several participants described the struggle that their spouse, children and friends had related to their stroke and how difficult it was to realize the effect they were having on the people about whom they cared. For some, the stroke resulted in a divorce from their spouse; for others their spousal relationship was strengthened after much hard work and adjustment. Regardless of the outcome, each participant described having to navigate through their relationships in light of their stroke, often redefining them in the process.

One participant described how he didn't want to be a burden on his wife after the stroke. His physical impairments left him initially requiring assistance with mobility and personal care.

[I told my] wife ...if this is too much for you, you can go ahead and leave....I didn't want to be a burden...I don't think she deserves to have to stay home all the time and look after me. At the time that's the way it was...I had to have somebody ... she had to dress me ...I told her, you can have everything...you deserve it...I wasn't saying it to be mean to her ...I just said, if you feel like you have had enough. Just tell me. (P007)

Another participant described how he and his wife are still working on their relationship, 18 years after his stroke. Prior to the stroke, he had prided himself on being a 'handy' man. He

would do all of the physical work around the house and really enjoyed being able to take care of his property and fix things. His severe hemiplegia prevented him from doing those types of tasks after the stroke. He described how these and other responsibilities were put on his wife.

The work load got put over to [my wife] which was very stressful for her being that she already had...a full time job. She had a child...my son [was five] and then we just had a newborn. So...I'm sure she felt a lot of the stress on her...we are still working on it...it's still a work in progress really...I understand it from her point of view that...it's tough. She is tired a lot. She is a lot more tired because she has a lot more to do now... with people having strokes ... it's the whole family that has the stroke. (P011)

One of the participants described how her marriage was no longer tolerable after her stroke. She explained that her husband had suffered from alcoholism for years before her stroke. She realized soon after her stroke, that the stress of her marriage was magnifying her deficits, and she felt as though she was getting sicker. She decided that in order to recover, she needed to end the marriage as soon as possible.

In that first year [after the stroke]...[I didn't understand] why I felt like I was getting sicker. But the stress of living with [my husband, who was an] alcoholic was making me sicker and more incapacitated. And so I just finally bit the bullet and ...[I left my husband]...once I had enough energy to, you know, pick myself up and drive my car to a different location. (P005)

Another participant described how her residual stroke deficits and inability to resume managing the home and parenting her young children resulted in tremendous strain on her relationship with her husband and family. She revealed that her husband had difficulty adjusting to her deficits and this resulted in his increased anger and frustration. After a lot of hard work and counselling their marriage dissolved.

...My husband and I were having real problems ... My husband had a really hard time accepting what was going on....Prior to my ... stroke... I was the very energetic wife, mom, career orientated. I'm the woman who looked after the kids, did the grocery shopping, did the event planning around our family life and all of a sudden I'm out of that picture. The husband now has to dive in who really isn't used to participating all that much. So the husband thinks that he is doing an amazing amount of helping out when he's really doing a small portion, but for him that's a larger portion than he did before I had the stroke. So, that's where the frustration would come in on his part and the anger. He was angry. He was

very angry. And who else to take it out on but your family and I'm the one that it got aimed at. (P010)

A new job experience exposed her to other people who were in a similar life circumstance to hers and she gained great insight and even some peace from their experiences.

I saw that 98% of the time if the physical disability or accident happened to the woman, happened to the wife, the majority of men left. If it would happen to the man, the husband, the majority of women stayed....that gave me a little bit of peace actually. It helped me understand that what my husband [did], how he reacted... it wasn't nice and he didn't have to be that way but [it was] a little typical. (P010)

Another participant believed that his inability to resume paid work contributed significantly to the dissolution of his marriage after the stroke.

I worked, my wife did not. We had kids. [Work] was a huge priority....Marriage was a huge priority and then my kids were a huge priority.... [One year after the stroke, my wife and I] kind of separated in our house. [Two years after the stroke] I moved [out]....I think it's just a change of lifestyle really [that lead to the separation] ...I hate to speak for other people but ...my perception of it is just ... that life had changed considerably....[she] didn't sign up for this...[Early on] there was always a hope..[or] an expectation....that you'll get better and you're going back to work...So, over the course of the year I think that expectation...had become more of a realization that he's not going to be going back to work. [I wondered if it was because I was] less competent than I used to be...I'm not...the same person ... [She told me] I'm having a hard time with it and ...it's my turn [now] to ...deal with things... We've been dealing with you for a year and now it's my turn to deal with myself. (P009)

The same participant described how he had heard about similar experiences from other persons after stroke.

I've heard other stroke survivors speak about this.... there's one...who said her husband told her, I don't quit you, I quit the stroke and he left her. And it's like, well I want to quit the stroke too but I can't, you know? (P009)

Participants' relationships with their children were also significantly impacted after the stroke. Being a parent was revealed as one of their fundamental life roles and participants expressed devastation with confronting the reality of what that would look like post-stroke. Their children also had to go through multiple adjustments as well, as they navigated their way

through family life after stroke. One participant described how her young son was fearful of her having another stroke.

[My son was] scared [after the stroke]... there [were] 2 instances...where [I was late to pick him up from school]... I found out [later] that [each of those times] he thought I had [had] another stroke. (P001)

Another participant described a particularly upsetting experience while she was in the hospital for stroke rehabilitation.

When I lived in rehab, [my husband] would bring the [kids] every Wednesday night so we could visit. And [on] one occasion he brought his mother with him and ...it was so upsetting ...my mother-in-law had my [children] calling her momma. I'll never forget that. I'm ... in a wheelchair, stuck in frickin' rehab, I'm paralyzed, my life has fallen apart and there is my mother-in-law telling my kids to call [her] momma. (P010)

She also described the many adjustments that she and her young children had to make throughout her stroke recovery. There were moments of inspiration, when she described how they practiced motor tasks together, as part of her rehabilitation.

My [one child] was learning [how to do zippers]... [so] once I started to get some movement back...in my arm and my hand, [we'd] learn how to zipper zippers...and tie shoe laces [together]. [We also] used to practice throwing balls [together]....Once I got my fine motor controls back, [my other child] and I would sit at the kitchen table we would learn how to print together. My kids were my inspiration. They were my true inspiration. (P010)

She also described how it did not take long for her children to figure out that she could not do certain things for them, so they quickly learned to stop going to her and started going to her sister for help. In the beginning, this was a devastating experience for her.

It didn't take very long for [them] to figure [out that]... mom can't do certain things so mom is not the one to ask, so we go to [my sister]. [She is the one] that they would go to all the time to ask for things and that was absolutely heart breaking for me...so I'd go off somewhere by myself and cry because it was sad. It was very sad. I couldn't run this house the way I used to. And my kids weren't looking up to me for help and a mom always... always counts on their kids running to them and looking at their big eyes and helping them but I couldn't and they figured that out all on their own really quick. So yeah it was tough. (P010)

She goes on to describe how she and her children had to adjust again as she began to get stronger and make progress in her stroke recovery.

Once I started becoming more independent and stronger... [it was time for them to] ... come to mom. I am the one who can deal with this. I'm the one that can help you. That was an adjustment; the kids had to go through many adjustments. (P010)

Another participant described how sad his child used to be about his stroke and his residual physical deficits and how this broke his heart.

[My one child] only knows me ... in my stroke body...my [other child] ... knew me before the stroke...and...remembered everything about me before my stroke... [and] used to get sad for the longest time about the fact that I was like this...Which really hit me in the heart. (P011)

Another participant described how his stroke impacted on his relationship with his children.

[My relationships] with the kids have gotten weaker for sure [since the stroke]...it's just again the element of time that's not being spent [together]...My [one child]... doesn't really remember me [before the stroke]...[and] is not very accepting of [my deficits]... I don't think [there's] an understanding that things are different....[and] has said to me over the past couple of years... Dad, I'm kind of sick of hearing about stroke. Can we not talk about it anymore? ...My [other child] remembers the healthy me and....[knows] that I used to play [hockey] really well...So definitely sees the difference between pre-stroke dad and post-stroke dad...[and] still has a ... pretty strong hope that one day I'm back to skating with and doing stuff again. (P009)

All of the participants described how the stroke impacted on their social lives and friendships. Some friendships with colleagues were lost as a result of an inability to return to work. One participant revealed disappointment that his belief in unconditional friendship was not upheld.

They were my friends and of course once I had the stroke... I wasn't working anymore so I wasn't near them anymore ... the phone stopped ringing more or less ...nobody was trying to pal around with me anymore and I mean I couldn't do the things I used to do. I couldn't go golfing with them anymore or ... hang out at the bar... [go for a beer]... or whatever after work. We had nothing in common anymore. I had a stroke and they still had their normal lives...and I understand that they have their own lives... But, the friendship part about it I don't understand because I thought a friend is a friend no matter what happens to them...But I guess some people aren't like that...and [there's] nothing I can do to control that (P011)

Several participants described the stress associated with trying to maintain old friendships steeped in expectations of the ‘old them’. Many participants experienced a loss of old friendships and a gain of new friendships with people they had met since their stroke, and therefore accepted them for who they are now.

One participant described how she felt the stroke had aged her. Her residuals deficits imposed limitations on her energy and abilities to engage in leisure activities and socializing. She felt as though her friends perceived her as growing too old too fast, almost as though they didn’t want to face their own morbidity through spending time with her after the stroke and so they avoided her.

...The best thing that you can do for yourself [after the stroke] is make new friends because overwhelmingly, all stroke survivors...have lost old friends. They very rarely call, come around or stay in touch...[Your] old friends see [you] as getting old overnight...[you] have moved into a bracket of friendship that these friends aren’t willing to move into yet. They have another 30 years before they get there...[so] it’s better to just not visit, it’s better to just not keep in touch. It’s better to just not phone. It’s better to just not email because...[we] have moved into retirement too quickly... [They’re] still running marathons and ... and climbing Mount Everest...so I think there’s a gap in friendships...and so one of the largest things facing all stroke survivors...is [that]...friends, drop off at an alarming rate. (P005)

The same participant described the stress of maintaining old friendships with high expectations that you can no longer meet. She explained that for her, the new friendships she made after the stroke were the best friends because they understood and accepted her for who she was now.

[My closest friends now] are the people that have met me since my stroke...They want to be my friends because they like what they see...post-stroke me is very different from pre-stroke me...they have met me right where I’m at and... they know what they see is what they get and that is acceptable to them in our friendship. (P005)

If we need friends, they have to be new friends, they can’t be old friends. Old friends are too taxing. And we need to be careful what we subject ourselves to...They stress you out too much. They want you to do a million things in a day...They don’t understand why you can’t. (P005)

Maintaining old friendships had also been a challenge for another participant. He described how being in old social circles highlighted for him how much he had changed.

You find new friends...people that can deal with you now. It's not [just] people that can deal with you now, but it's people that you now can deal with as well... I've gone back into my old circles...it's very hard for me to go back into [those] worlds...I still have a hard time with that...[you become aware] of knowledge that doesn't seem to be there anymore... and realize ... that, you don't have the same self-esteem...your self-esteem is gone...it doesn't feel like a good fit anymore.....So you find new friends...and it really does help to get your self-esteem back.(P009)

Authors of the autobiographical descriptions described similar experiences related to wanting friends that accepted them as the person they had become since the stroke.

I'd been looking forward to meeting people who didn't know me before. No comparisons, no 'she used to be a filmmaker' or 'you must miss tennis'...just what is...now. (BSK, 1997, p.261)

I desperately needed people to accept me as the person I was at that moment, and permit me the freedom to evolve as a right hemisphere dominant personality. (JBT, 209, p.119)

There were some positive experiences expressed by some participants with regard to relationships with their parents. Their parents were often still young enough to be engaged and in retirement which resulted in them having the time to dedicate to supporting their adult children during their stroke recovery.

One participant described how his stroke actually resulted in a reconnection with his estranged mother, a relationship that had become very significant to him.

Actually the [relationship] with my mother got stronger...she lives [out of province], she moved away when I was [young]...and we really didn't contact each other too much. Since my stroke, I bet you we've talked on the phone every single day. (P009)

He also described that his relationship with his father had also been strengthened through the need to spend more time together.

Even with my father, I seem to spend more time with him too... [because]... I make a point once a week to go there and visit with him, do laundry, help him with his computer

problems... He takes me to Wal-Mart or something so ... I think the relationships I have with my parents ...definitely have gotten stronger. (P009)

The concept that the parental role becomes activated despite the age of the child was repeated again, as a participant described the integral role that her father played in her stroke recovery.

When I lived in rehab, [my dad] came and had lunch with me every single day and dinner with me every night... [I was]determined [to eat] on my own...and dad would sit at the table and watch me trying to take my fork and stab a potato and half the time I'd stab the wrong thing because [I had] double vision and I couldn't hit the potato. And dad would look at me with his big eyes... his big blue eyes and I could see the tears behind his eyes... just wanting to help...[but] no, no I can do it myself, I'll do it myself. [Those were] my three famous words, do it myself. (P010)

As participants experienced living with stroke and realized that they would not likely be without deficits, they began to re-evaluate their lives and their relationships, they began to redefine themselves and their life roles, and started to figure out how to move forward. As the participants described it: “It’s time to own the stroke” (Blog, Jan 31st 2011)... “You have to deal with the fact that you have problems and you have to adapt to live life despite them” (P009).

Theme 5: Carrying on.

Once participants accepted that their life as they knew it pre-stroke had changed, they began to re-define, adjust, adapt and accept who they were becoming. As was mentioned previously, there is a definition of occupation that includes “all that people need, want, or are obliged to do; what it means to them; and its ever-present potential as an agent of change. It encapsulates doing, being, and becoming” (Wilcock, 2006, p. 343). ‘Doing’ in this sense refers to being engaged in purposeful doing; from the things that you must do like daily tasks and work, to the things that you want to do like social and leisure activities. ‘Doing’ is how most people occupy their time every day (Wilcock, 1999). ‘Being’ encapsulates “being true to ourselves, to our nature, to our essence...to ‘be’ in this sense requires that people have time to discover themselves, to think, to reflect and to simply exist” (Wilcock, 1999, p. 5). ‘Becoming’ adds a

future sense to the concept of being. Becoming includes the belief of potential, growth, transformation and self-actualization; every person requires a personal, yet dynamic balance of doing, being and becoming in order facilitate health and well-being (Wilcock, 1999). Doing, being and becoming are all integral components of community reintegration. The theme of carrying on will be framed within this context.

Prior to the stroke, participants lead highly productive and active lifestyles; they were busy ‘doing’ all the time. Their stroke left them with residual deficits that presented a barrier to their ability to resume this type of active lifestyle. The participants described great fear, guilt, inadequacy and sadness regarding their inability to ‘do’. They also revealed the negative impact of not ‘doing’ on their self-worth, self-esteem, self-confidence and self-identity, which also impacted on their overall life satisfaction and well-being. One account described the frustration of no longer being able to ‘do’ things that seemed so easy before the stroke.

How exasperating it is no longer to be able to do what seemed nothing at all. (MS, 1988, p.31)

Several participants identified work as one of their main purposes in life.

I get up every morning and I go to work which means...there's purpose in life. (P003)

[Teaching] was my purpose in life....[not being able to return to work] makes you feel a number of things...sad...frustrated...it makes you feel like you're being abandoned in that you are instantly disposable...and none of us wants to feel like that. (P004)

Another participant described the feelings of guilt and inadequacy that she experienced as a result of not being able to return to work. These feelings were exacerbated by her colleagues’ perceived lack of understanding regarding her residual, ‘invisible’ stroke deficits.

I just get this sense that [my colleagues] think well why aren't you back, you come to visit, you look normal ... what do you mean you're not teaching? So [the guilt] was eating me upI just feel like sometimes I can't contribute...I don't have anything to contribute because I'm not doing things...[My colleagues would say]...well aren't you going crazy...[aren't you

bored]... and I thought, ... I'm not going crazy. You know they're so bored, they're on their laptops and I'm thinking I can't even read my laptop. (P001)

One participant recognized that he would not be able to return to his manual labour job due to his residual physical deficits, he explained that he would need to find a different type of job and would need to 'do' differently. He revealed the importance of working and being independent to his life satisfaction.

I understand I'll never be like I was before and I can accept that...[as long as I can get back my] independence and [get back to] working... it might not be the same job... but [if] you are working and you are independent [then]... you get your life back...I'm looking forward to getting myself physically fit so I can get a job ... because you do need money...like my daughter is young, she's going to get married one of these days. I think about that already...because it's going to happen...It can be minimum wage...I don't care what kind of job it is (P007)

The financial implications of not being able to return to work and to be paid for 'doing' became a reality for other participants.

The hardest thing and this is unanimous among stroke survivors is accepting. Getting to a place of accepting....That you won't provide for yourself monetarily. Everything else was acceptable. (P005)

Participants then described evolving to a level of awareness that they needed to carry-on with a life that was not focussed on a job, money and doing. For some that meant having to 'do' differently, for others it meant completely redefining the role that 'doing' played in their lives.

It becomes very apparent that time is so much more important than spending all [of it] working at a job, making money and [buying] things ...I worked for 23 years and got a lot of things and all [those] things are gone...[and] what do you have left? Some experiences. I have grandparents that are dead, I don't have many of their things but I do have experiences with them...I remember their laughter at birthday dinners or Christmas ...those are the things that you come to realize are most important...the time things...It's not the monetary things at all...I saw an expression not long ago about the best way to express love is time. It's not the things that you buy ... so with my kids for example...I can't buy them stuff anymore...But what I can give them is time. So I can spend time to coach them, or I can spend time hanging out and cooking...watching a movie...or go to the library. We can spend this time [together], [I was so busy working that] I wasn't spending that time with them before. (P009)

The same participant continued to describe his new found appreciation of quality time; spending time with the people in his life, rather than ‘doing’ or providing for them.

[I was] busy, busy, busy all the time [before the stroke]...and you reflect about your kids saying [they didn't get to spend enough time with you]... and you turn to your friends and say man, you know what? Slow down...Before something like this happens and forces you to slow down. But everybody's always got the same response, you know, I can't. I've got bills to pay; I've got things to do. That won't happen to me. It's like, well... hopefully it doesn't but ... you should be trying to spend your time wisely. Whatever time you have... it should be wiser. (P009)

As participants redefined and accepted the new role that ‘doing’ would have in their post-stroke lives, ‘being’ emerged as a significant component of this theme. Participants recognized the connection that ‘doing’ had to their self-identity, self-confidence and self-worth. They revealed a need to redefine themselves and needed the ‘being’ time necessary to do this. In this sense, the act of ‘being’ could be considered ‘doing’, as it required dedicated time to think and reflect and simply be with themselves. Several participants described how positive the experience of letting go of ‘doing’ and embracing ‘being’ was to them. They were not only redefining themselves but also redefining their life after stroke.

I think stroke recovery itself is a job...just getting up in the day, remembering what I'm doing ... showering, getting dressed...it's quite amazing how full my day is considering I don't have a job. (P009)

I'm amazed at how well I'm doing, doing nothing. The days simply unfold. Even days that are empty of plans are full of surprises. I think I'm learning how to live. (BSK, 1997, p.267).

I think out of anything... [meditating and mindfulness]... have helped me realize that I'm happy with what I'm doing. I get to help my son with the difficulty he's having, I get to walk him to school every day. I'm taking the steps slowly, but I'm happy, I'm okay with not working. Not the money part of it but the day-to-day. (P001)

Jill Bolte Taylor's (2009) pre-stroke life had been consumed with ‘doing’. She provided great insight into how her stroke influenced her ability to understand the true meaning of ‘being’.

I look into the formless abyss of a silent mind, where the essence of my being became enfolded in a deep inner peace. (JBT, 2009, p.xiv)...In this altered state of being, my mind

was no longer pre-occupied with the billions of details that my brain routinely used to define and conduct my life in the external world. Those little voices, that brain chatter that customarily kept me abreast of myself in relation to the world outside of me, were delightfully silent(JBT, 2009, p.42)...I had forgotten about my job and all the things in my life that brought me stress – and with this obliteration of memories, I felt both relief and joy. I had spent a lifetime of thirty-seven years being enthusiastically committed to ‘do-do-doing’ lots of stuff at a very fast pace. On this special day, I learned the meaning of simply ‘being’. (JBT, 2009, p.70)

Several of the participants described an increased sense of being in the present, of living moment to moment as they discovered and reinvented their new self and their new normal.

I have learned something in these months of not being well...to live moment by moment....being alive as far as I am able to the instant. (MS, 1988, p.19)

I am reminded that is how life is, we don't have to be the best we just need to try our hardest and own the piece of life we are living...one minute, one task at a time (Blog, Feb 16th 2011)

All of a sudden the future was gone, too fragile to imagine, and there was just the moment. (BSK, 1997, p.175)

This period of re-evaluation and re-definition required time that was dedicated to thinking and reflecting, in order to determine who they wanted to be post-stroke. How was the role of mother, photographer, or hockey coach to be now? One participant described the transformation he made to his previous roles.

Hockey [I do now] from the bench, I'm just dealing and adapting again...I was always the head coach...I'm not now; I'm more of an assistant coach...I cannot stand on the bench for risk of falling...and I don't skate anymore, balance is too bad. (P009)

I still do as much [photography] as I can...but I got rid of all my professional gear, it was too much to carry around. And I bought a high end point and shoot camera, which you really can't tell the difference between the pictures. (P009)

Others described the re-creation of their new normal.

[Four or five years after the stroke]... the [kids] and I went skiing up in Collingwood... it was a beautiful blue day... and I was at the top of the hill...[overlooking] Georgian Bay and I was standing there ... looking at the blue sky. Thinking oh my God... here I am again, this is it...I am back again...It's almost as though you were then creating a new normal. (P010)

I started to figure out how to live as my new self. This meant getting to know other people with disabilities, and becoming part of the growing movement for disability rights. (BSK, 1997, p.xi)

Becoming, captures the participants' journey about who they were before the stroke, to who they are now since the stroke as well as who they envision they will be in the future. In this sense, it reflects their past, present and future self. Participants were now facing a new future.

I needed those around me to be encouraging. I needed to know that I still had value. I needed to have dreams to work towards. (JBT, 2009, p.119)

That is what I have learned to do...with lots of help...to stop looking for a cure and get on with living (BSK, 1997, p.71)

As participants let go of their pre-stroke lives, they entered into a phase of adjustment, adaptation and redefinition. These experiences ultimately led them to a place of acceptance and from there participants transitioned to transcendence.

Theme 6: Transcending the stroke.

The word transcend derives from the mid-14th century Latin term 'transcendere' and means to "climb over or beyond, surmount" (Harper, 2013). Each of the participants arrived at a place of transcending their stroke and described an element of being better now because of the stroke. While the reason for being better varied amongst the participants, the notion of rising above and achieving some form of gratitude was a common element of this theme.

Several participants described gratitude for the increased time that they were able to spend with their families after the stroke.

I tell people that was one of the best things that happened out of the whole stroke situation. Being able to spend time with my [child]...[I got to] focus more on my family and... my young [children] and ... That's one thing about the stroke that I would never ... want to give back. The time that I had to spend with my [child] during the first few years of life...that was beautiful. (P011)

Another participant described how her stroke gave her a renewed perspective on life and helped her to reset her life's priorities. She gained a new found appreciation for life.

We are not going to say oh I wish I could have worked more...We are going to say I wish I could have spoken to my child more or my spouse or my friend...[the stroke]changes us...I think in some ways I'm better, I'm a better person for the stroke...I didn't get it right before...my priorities weren't right...we will never take anything for granted again, we can enjoy the little things. (P004)

One participant revealed how the stroke opened up a world of possibility for her. As she reflected after her stroke experience, she realized that her so-called 'perfect' life pre-stroke, hadn't really been perfect at all. She described her life as being better because of the stroke.

I appreciate what I have been given through this journey. This journey of struggle, this journey of sadness, frustration, and change... and at the end of it all life is so much better because of all of it...It feels sometimes to me as if my life was in ... a shoe box. I had a [great] job...I made a lot of money. I had three beautiful children, a really nice home, a supposedly happy marriage. Life was good. And it feels for me I had this opportunity to go through this little tiny hole at the top of this box. I go through this little tiny hole and there is blue sky that goes on forever and ever... [with]endless opportunities. And that life is bigger than I knew it to be. (P010)

Another participant described his transcendence experience in the context of a lifecycle. His stroke resulted in the birth of some positive aspects such as spending more time with his children and new friendships, and resulted in the death of some negative aspects such as unhealthy relationships and a stressful job.

There is a birth of everything right? Like the birth of being able to walk your child to school and....there's a birth of other things that happen, [like new] friendships...[There is also death] ...the death of jobs that maybe weren't the best things for you...that put too much stress on you...[the death of relationships that weren't the healthiest for you]. So you know, the death on one side of the stroke is ... what it is, but I think there is a lot of birth... rebirth that happens as well with it and it may actually wind up being the best thing in the long run...I'd have to say life is probably better despite the fact that things are maybe not that great physically or mentally or financially...it's a different pace to life that's for sure...I believe I worry less now than ever...I'm not so consumed with work and bills and debt ...the spotlight isn't on those things anymore...So that helps tremendously...Now the spotlight is on feeling well, getting up and doing things...There's a simplicity to it all. (P009)

Although none of the participants indicated that they would have chosen to have a stroke, in their own unique way, they have each transcended their stroke and have described how they have risen above it and have become better because of it.

I wouldn't have chosen to have a stroke and live the rest of my life as I am now, but it's what I've been dealt and I'm pleased with myself for making the best of it. While I don't want to idealize bad luck, we are more than our bodies, and there's more than one way to fly. (BSK, 1997, p.79)

Lifeworld Existentials as Guides to Reflection

Van Manen (1997) suggested that there are four fundamental lifeworld existentials that can serve as helpful guides for reflection during the analysis process: lived body (corporeality), lived time (temporality), lived space (spatiality) and lived human relation (relationality or communality). These existentials are considered to be fundamental to the way that all human beings experience the world and are therefore important elements to be included in the interpretive phenomenological approach (van Manen, 1997).

Lived body refers “to the phenomenological fact that we are always bodily in the world” (van Manen, 1997, p. 101). The significance of lived body became evident early in the analysis and was a significant element of each of the themes. Stroke often results in residual motor, cognitive, perceptual or mood deficits. Each of the participants experienced some type of residual deficit after the stroke, which shook their taken for granted assumptions about having a smooth functioning body and mind. This affected the relationship between their bodies and their selves, which ultimately impacted on their self-esteem, self-confidence and self-identity. The analysis revealed not only the significance of lived body to the experience of community reintegration but also the impact that lived body has on the other lifeworld existentials of lived time, lived space and lived human relation.

Lived time refers to subjective time as opposed to clock time and also refers to our temporal way of being in the world through the dimensions of past, present and future (van Manen, 1997). All of the participants described being in the prime of their life before the stroke. They shared experiences from their pasts that reflected being very active, very productive and very engaged in their lives. Participants used words such as “Type A Personality” or “Energizer Bunny” to describe themselves before the stroke. Both idiomatic phrases are used to describe high-achieving, multi-tasking, untiring individuals. Since common expressions tend to be born out of shared lived experiences, this was extremely insightful with regards to understanding how the participants perceived themselves before their stroke and how it might shape their recovery and reintegration back into the community. Their overly productive pre-stroke lifestyle exacerbated their discontent with their less productive, less busy present and raised concerns for their future. Participants had to re-evaluate their past and re-define their present, thus creating a new normal and vision for their future.

The journey itself, of surviving a stroke in the prime of your life, also revealed several temporal components. Participants experienced shock that they had sustained a stroke and faced their own mortality and morbidity at such a young age. This experience imparted a new found appreciation of being alive, which translated into a greater focus on living in the present moment and seeing every day as a new day. After processing the initial shock of the stroke and experiencing gratitude for being alive, participants were faced with a new reality of living with stroke and a realization that they may be changed forever. Participants described how the memories of their past committed them to a focus on getting back to normal. As time passed, they began to realize that they might not regain their former unimpaired selves and would need to reach some level of acceptance in order to be able to “move on”. They described shaken pre-

conceived notions of what their ‘working-aged’ years were going to be like, full of productivity and promise. They also described dashed hopes and expectations related to what they had perceived for their future. Ultimately however, their journey led to adjustment and carrying on and ultimately to a place of transcendence, with each participant eventually rising above the stroke.

Lived space refers to “felt space...it is a category for inquiring into ways we experience the affairs of our day to day existence” (van Manen, 1997, p. 102). When we want to learn about a person we often inquire about their spatial world, their background, place of birth, childhood, interests and profession. These spatial elements are integral components of our past and present, informing who we are. The home, for example, contributes to our sense of being. “Home is where we can be what we are” (van Manen, 1009, p.102). Our homes are a secure sanctity that offer protection and privacy from the outside world (van Manen, 1997). We go home to them at the end of every day. They are the spaces within which we share intimate moments with our spouses, families and friends. Spatial components to community reintegration revealed themselves throughout the analysis. Once participants had their stroke, they were taken to the hospital. Several participants spent an extended period of time in the hospital during their initial recovery. Participants described discomfort with the institutional hospital environment. They felt misunderstood and frustrated by the hospital staff and all experienced a strong desire to return back home. However, once participants were finally able to leave the hospital and return home, they experienced new spatial challenges. The environments in which they were accustomed to functioning effortlessly such as their home and their community proved to be difficult as they tried to navigate these spaces with residual stroke deficits.

The final lifeworld is lived human relation, which is “the lived relation that we maintain with others in the interpersonal space that we share with them” (van Manen, 1997, p. 104). This captures the importance of relationships in our lives. Participants described how their stroke impacted on several important relationships. Life after stroke caused strain on marriages, it impacted on relationships with children and revealed feelings of lost friendship. All of which contributed to a sense of unfulfilled life roles as spouse, parent, friend and social being. Participants had to redefine their relationships and life roles as they navigated their way back to their life after stroke.

Summary

The essence of the phenomenon of community reintegration for working-aged persons post-stroke emerged as: The journey of surviving a stroke in the prime of your life. The six themes described above emerged to support this journey of community reintegration after stroke and are reflected in the overarching theme of “Life Goes On”.

The first theme “Processing the Shock”, captured the notion of stroke as an unexpected and traumatic experience. The second theme “Starting the Road the Recovery” reflected the early stages of recovery which often began with an element of being grateful to be alive and then transitioned to a focus of getting back to normal. The third theme “Living with Stroke” revealed the challenges of learning to live with residual stroke deficits. The fourth theme “Who Am I?” was related to the loss of self-identify that came with a changed body and mind after stroke. The fifth theme, “Carrying-On” highlighted the process of acceptance and moving on. The sixth and final theme, “Transcending the Stroke”, reflected the experience of each participant rising above the stroke and identifying some element of being better now, as a result of the stroke.

While each participant experienced their personal journey to community reintegration in a unique way, their journey led them to realize that in order to successfully reintegrate back into their community, they needed to adjust, adapt and reach some level of acceptance in order to move on and essentially transcend their stroke.

The results of this interpretive phenomenological study can assist stroke care providers, system planners and policy makers with: 1) Understanding the meaning of community reintegration after stroke from the working-aged study participants' perspectives, and (2) Applying the insights arising from this understanding to services and approaches that are sensitive to the needs of working-aged persons post-stroke. The next chapter focuses on how these findings fit current conceptualizations in the literature as well as future directions for research in this area.

5

Discussion

The purpose of this interpretive phenomenological study was to explore the lived experience of community reintegration for working-aged persons post-stroke in order to inform the development of appropriate and effective strategies to support their community reintegration and continued stroke recovery. The essence of the phenomenon of community reintegration for working-age persons post-stroke emerged as: The journey of surviving a stroke in the prime of your life. The analysis yielded six themes that supported this journey of community reintegration after stroke and are reflected in the overarching theme of “Life Goes On”. The first theme “Processing the Shock” captured the stroke as an unexpected and traumatic experience. The second theme “Starting the Road to Recovery” reflected the early stages of recovery, with a focus on getting back to normal. The third theme “Living with Stroke” revealed the challenges of learning to live with residual stroke deficits. The fourth theme “Who Am I?” related to the loss of self-identify that came with a changed body and mind after stroke. The fifth theme “Carrying-On” highlighted the process of acceptance and moving on. The sixth and final theme “Transcending the Stroke” reflected the experience of each participant rising above their stroke. Participants of the current study included 11 interview participants, three autobiographical authors and one online blog author whose experiential data were included in the analyses.

This chapter focuses on how these findings have contributed to the understanding of this journey as well as how they correspond with current conceptualizations in the literature. Possible implications for stakeholders are presented and recommendations made regarding practice and stroke service provision in light of the findings. The strengths and limitations of this study are discussed as well as suggestions for future research.

Findings in Light of the Literature

Processing the shock.

The participants of the current study described their stroke as a traumatic experience. They were shocked to be facing their own mortality at such a young age, at a time in their life when they felt strong and assumed they had a healthy and prosperous future ahead. Not only was the stroke a shock to the participants and their families but it was also confusing to the medical professionals who took care of them. This was demonstrated through delayed and missed diagnoses of several participants. Studies investigating the experience of living with stroke in a mixed sample of both working-age and older adults supported the finding of stroke as a shocking event. They revealed the stroke experience as being an unexpected and overwhelming catastrophe for participants that ultimately changed their lives forever (Becker, 1993; Burton, 2000; Dowswell et al., 2000; Ellis-Hill, Payne & Ward, 2000; O’Connell et al., 2001; Pilkington, 1999).

The significance of the participants’ ages to the identification and diagnosis of stroke was highlighted in a study by Stone (2005b). Both participants and the medical community experienced a delay in recognizing and diagnosing their strokes, due to their ‘young’ age. Similar to the current study, several participants commented on their disbelief that a stroke was happening to someone of their age, further supporting the common belief that stroke is a disease of older persons (Stone, 2005b).

Starting the road to recovery.

After processing the initial shock of having a stroke and facing their own mortality, participants from the current study initially described feeling grateful to be alive. This was followed by a focus on getting back to normal and resuming their pre-stroke lives. Participants

were hopeful that they would fully recover from the stroke and regain their former unimpaired selves. The term ‘recovery’ is derived from the Medieval Latin term ‘recuperare’ which means to “regain health, to come back, to get health back” (Harper, 2013). The meaning of recovery emphasises a return to one’s previous state and aligns with what the participants were expressing related to getting back to their old selves and getting back to normal. The term ‘normal’ is derived from the Late Latin term ‘normalis’ and means "conforming to common standards, usual state or condition” (Harper, 2013). Similarly, the etymological origin of ‘self’ means "one's own person, same" (Harper, 2013). At some point in their stroke recovery, each participant was focused on getting back to his/her pre-morbid self and life.

These findings were similar to those of a study by Dixon et al. (2007) that reported how persons after stroke engaged in a recovery model that ascribed ‘getting back to normal’ as the primary goal. The authors suggested that the rehabilitation environment itself may unintentionally contribute to the belief that a complete recovery is possible, even though in several circumstances it may not be possible (Dixon et al., 2007). The realization that they may not resume their pre-stroke condition proved to be difficult for participants to accept. Similar findings were evident in the current study, as participants reported their struggles with realizing that the stroke had changed them forever and that their desire to fully recover and resume their old lifestyles had become less of a reality. Dixon et al. (2007) observed that a focus on recovery and “getting back to normal” may interfere with the person’s ability to adapt and adjust to his/her residual stroke deficits and potentially serve as a barrier to maximizing daily functioning and participation.

The hospital environment for most participants of the current study was not ideal. They were surrounded by predominantly very sick, disabled, older people. Participants revealed feeling

misunderstood by the medical teams. They felt that their healthcare professionals did not seem to appreciate that they came from a different life situation than the older patients in the hospital. Participants described feeling as though they were part of a “cookie cutter” approach that was geared towards older adults and did not meet their needs. They did not feel as though they were receiving client-centered care.

Several authors have noted that inpatient rehabilitation programs tended to focus on older adults and did not meet the needs of younger persons post-stroke (Roding et al., 2003; Stone, 2005b). At the time of their stroke, younger persons were either in the paid labour force or planning to join it. They were also either responsible for young children or planning to raise a family. Rehabilitation strategies geared to older adults were not meeting their unique needs (Stone, 2005b). Furthermore, these participants also described not feeling engaged with their rehabilitation program, feeling as though they were passive participants walking beside the process as opposed to being actively a part of it (Burton, 2000; Roding et al., 2003). Staff were focused on the physical and functional retraining of basic activities of daily living, while the participants were more concerned with their ability to resume previously important activities and life roles, such as returning to work and parenting (Bendz, 2003; Lock et al., 2005; Roding et al., 2003; Stone, 2005b). These studies demonstrated a lack of client centered care, indicating that rehabilitation programs were geared to older adults and that there was a need for more age-appropriate activities and environments.

In addition to a lack of client centered care, participants from these studies also described feeling as though the medical team ignored their cognitive and more ‘invisible’ deficits which they expressed as a gap in their rehabilitation experience (Bendz, 2003, Roding et al., 2003, Stone, 2005b). Studies by Hommel and colleagues (2009) and Malm et al. (1998) further

supported this finding. Both studies found that cognitive impairments such as general cognitive functioning, memory, instrumental functions, executive functions and working memory significantly contributed to major challenges with community reintegration and return to work after stroke. They concluded that insufficient attention is paid to this component of stroke recovery during stroke rehabilitation. These results were similar to the current study's findings, where several participants experienced frustration and felt as though they were working against a hospital system that didn't seem to understand them.

This led to an investigation of the literature on the perspectives of recovery as viewed by health care professionals and persons with stroke. Doolittle (1990) reported that participants' definition of recovery was based on the ability to successfully resume previously valued activities, whereas healthcare providers' definition of recovery was based on improved basic functional abilities. Medin, Barajas, and Ekberg (2006) illustrated the health system's focus on medical as well as basic physical and functional recovery, which resulted in frustration by the younger persons post-stroke who experienced milder, more invisible deficits. Mild stroke is often defined as occurring in someone who has minimal physical impairment as a result of stroke, regardless of the severity of more 'invisible' deficits such as altered cognition, perception and mood. This population, including some participants from the current study, tended to describe feeling as though they fell through the gaps of our healthcare system, which is focused on physical and basic functional recovery.

This perception of "falling through the cracks" is supported by Edwards, Hahn, Baum, and Dromerick (2006) who discovered that 35% of persons who experienced milder strokes were discharged home from hospital with no further service, even though 87% reported residual deficits with attention, concentration, community mobility and decreased interest and

participation in social activities. The need for appropriate rehabilitation for those who have experienced mild stroke was highlighted as: “Higher order cognitive abilities underlie and support daily life performance; their impairment or loss compromises a person’s ability to fully participate in society” (Baum et al., 2008, p. 446). This observation has a direct impact on a person’s ability to successfully reintegrate back into their community and aligns with the challenges described by the participants in the current study.

Other elements of stroke rehabilitation were identified that might contribute to a more supportive and client-centered approach to the rehabilitation and community reintegration of working-aged persons post-stroke. Younger persons with stroke expressed a need for peer support and interaction with other younger persons with stroke (Dixon et al., 2007; Roding et al., 2003). Stone (2007) reported that regaining one’s sense of self should be considered as an integral part of the rehabilitation process.

The role that effort has in the person’s stroke recovery process has been described as the vast amount of effort required to get through their daily life after the stroke (Doolittle, 1990; Secrest and Thomas, 1999). Tasks that were once effortless were now effortful and resulted in frustration and fatigue. “The unreflected-on, taken for granted way of being in the world has now become a conscious effort” (Secrest & Thomas, 1999, p.243). Participants from the current study also described how much they took their previous life for granted: the automaticity and reflexivity of certain tasks like parenting and going to work each day. Since the stroke, they described the need to consciously think everything through, how nothing could be taken for granted and how exhausting this was.

Several authors have also reported on the role of control in life after stroke (Burton, 2000; Doolittle, 1990; Secrest & Thomas, 1999). Persons often described their stroke as something

over which they had no control, as well as reported feeling as though they had lost control over their bodies and life in general since the stroke. This contributed to frustration and a disconcerting feeling which further threatened both their ability to cope and their sense of self (Burton, 2000; Secrest & Thomas, 1999).

Living with stroke.

Participants from the current study came to the realization that they would have residual deficits from the stroke and would not likely reclaim their former unimpaired selves. For some of the participants who experienced mostly ‘invisible’ deficits, they described the struggle of being misunderstood, feeling as though no one, from their own family to the community at large, understood that they continued to experience residual but invisible deficits. All of the participants described their struggles with completing basic activities of daily living, engaging in meaningful activities such as paid employment and resuming important life roles. This realization that they may not regain a smoothly functioning mind and body impacted on the relationship between their body and their sense of self, and often resulted in a loss of self-esteem, self-confidence and self-identity.

The literature related to living with residual ‘invisible’ deficits after stroke is similar to the findings of the current study. Stone (2005b) concluded that the widespread belief that working-aged adults are not susceptible to stroke, makes it even more challenging for working-aged persons with stroke and those around them to make sense of their residual and often invisible stroke deficits. She described the challenges that persons with invisible deficits experience with regards to their presentation of self. Others do not as readily accept that persons with invisible deficits have a problem that needs to be considered, in contrast to people whose deficits are visible (Stone, 2005b). Therefore, people with invisible deficits must consistently decide

whether or not they want to disclose their deficits. “If they keep quiet, they run the risk of being judged as lazy, incompetent or something else equally derogatory. If they tell, they run the risk of not being believed, of being judged as inappropriately looking for sympathy, or of simply being an attention-seeker” (Stone, 2005b, p.300). This dilemma imposes a constant fear of being misunderstood (Stone, 2005b). Frustration has also been described related to not being able to meet the unrealistic expectations imposed by people who did not understand. In addition, disappointment and exasperation were experienced with those close to them, who commonly forgot about their deficits. Stone (2005b) concluded that the young persons with stroke included in her sample, were not sufficiently prepared for successful community reintegration: “having to negotiate everyday life within a social context that neither acknowledges that young people can experience stroke, nor acknowledges that not all disabilities worth taking seriously are readily visible” (p.303).

Röding, Glader, Malm, and Lindström (2010) reported that the ‘invisible’ deficits residual from stroke impacted on participants' life satisfaction and were described as being more challenging than their more visible deficits. Participants felt that the ‘invisibility’ of their deficits made them feel less legitimate and that they were often misunderstood by others. Similarly, Stone (2005b) reported that her study participants believed that their deficits needed to be visible in order to be taken seriously. The participants in a study by Murray and Harrison (2004) also described the challenge of living with invisible deficits after stroke. Several reported that they would have preferred to have a visible disability in order to evoke more empathy and understanding from others. They struggled with feeling as though their deficits were not acknowledged or accepted by others (Murray & Harrison, 2004).

Another major concern effecting life after a stroke is fatigue. Roding et al. (2003) reported on the overwhelming impact that fatigue had on participants' stroke recovery and community re-engagement. Participants described fatigue as the main reason for not being able to resume full time work as well as actively engage in their family and social lives. Their fatigue prevented them from engaging in daily life and resulted in decreased life satisfaction (Roding et al., 2003).

Post-stroke fatigue prevalence rates are reported to affect 33% to 77% of persons post-stroke and are reported during both the acute and chronic stages of stroke recovery (Crosby, Munshi, Karat, Worthington, & Lincoln, 2012; Hoang et al., 2012; Michael, Allen, & Macko, 2006; Parks et al., 2012; Radman et al., 2012; Schepers, Visser-Meily, Ketelaar, & Lindeman, 2006; Winward, Sackley, Metha, & Rothwell, 2009). Although post-stroke fatigue is common after stroke, there appears to be a lack of awareness of it among healthcare providers, resulting in it being under-diagnosed and inconsistently assessed and managed after stroke (Crosby et al., 2012; Parks et al., 2012). There is a lack of consensus regarding predictors of post-stroke fatigue, which likely reflects its multifaceted nature (Feigin et al., 2012; Hoang et al., 2012; Parks et al., 2012; Radman et al., 2012). Younger participants described post-stroke fatigue as one of their worst symptoms post-stroke. It is believed that younger persons post-stroke experience an increased burden of fatigue as compared to older persons which had important implications for their stroke recovery and quality of life (Parks et al., 2012). Although post-stroke fatigue has been shown to occur frequently after stroke and negatively impact on instrumental activities of daily living (van de Port, Kwakkel, Schepers, Heniemans, & Lindeman, 2007), return to work (Anderson, Chrestensen, Kirkevold, & Johnsen, 2012; Radman et al., 2012) and quality of life (Parks et al., 2012; Tang et al., 2010; van de Port et al., 2007), it often remains unaddressed by the healthcare community. This may be due to the fact that there are

currently no evidence based treatments for post-stroke fatigue (McGeough et al., 2009; Parks et al., 2012) which results in clinicians being unsure of how to manage this condition. Further research is needed to better understand the features of post-stroke fatigue as well as effective interventions for its prevention and treatment (Parks et al., 2012).

There are several challenges of living with invisible deficits post-stroke, including how they can undermine a person's credibility with health care providers and contribute to a lack of understanding by those closest to the person. Charmaz (1995) revealed how young age can further exacerbate this challenge, "youth and beauty render an invisible illness even more invisible" (Charmaz, 1995, p.666).

Who am I?

Participants in the current study revealed the impact that their deficits had on their self-esteem, self-confidence and self-identity. They also described how their loss of normalcy and inability to resume certain meaningful activities and life roles resulted in an erosion of their sense of self. Participants revealed feeling scared, deprived and confused regarding their self-identities as the roles and activities that once defined them had become challenged by their inability to participate fully in them. This was the beginning of their reflective journey of self-evaluation. Martin Heidegger (1969) believed that people's identities were only truly formed after the experience of confronting their own death. He felt that most people were trapped by a socially constructed identity of 'how they should be', and that it was only through the experience of facing their own death that they generated the clarity and freedom required to truly define themselves (Heidegger, 1969).

Dowswell et al. (2000) referred to a sense of 'rolelessness' that enveloped persons post-stroke. Participants were unhappy with their transition to being receivers instead of 'doers' after

the stroke which resulted in participants feeling unfulfilled and passive (Dowswell et al., 2000). In a study by Morris (2011), residual stroke deficits prevented working-aged persons from interacting with their peers and resuming normal age-related activities such as parenting, working and socializing. This resulted in a discontinuity between their pre-stroke self and their current self (Morris, 2011). Female participants in a study by Roding et al. (2003) described frustration with the demands that they felt they had to live up to, with regards to role expectations and abilities. Most participants expressed feeling fully responsible for their home and family lives and felt that they were unable to fulfill these inner and external expectations (Roding et al., 2003).

Evidence suggests that this discontinuity between the pre-stroke and post-stroke self significantly impacts on a person's ability to define who they are now and the role they play within the community. Participants from studies investigating the experience of living with stroke in a mixed sample of both working-aged and older adults described the stroke as significantly impacting their ability to engage in meaningful activities, resume important life roles and maintain relationships, which subsequently disrupted their sense of 'self' (Burton, 2000; Ellis-Hill et al., 2000; Murray & Harrison, 2004; O'Connell et al., 2001; Secrest & Thomas, 1999). In an attempt to resolve the tension between their present self with their pre-stroke self, participants embarked on a journey of re-evaluation and re-definition which often resulted in some form of transformation and the development of a new identity inclusive of their deficits (Becker, 1993; Murray & Harrison, 2004; Secrest & Thomas, 1999). The literature supports the suggestion that working-aged persons with stroke experience a loss of self-identity.

Participants from the current study also revealed the impact that their deficits had on their relationships with family and friends. Several participants described the struggles they

experienced with their spouses, children and friends. Several participants described the strain that was put on their marriage as a result of the stroke. They also described the stress associated with trying to maintain old friendships steeped in expectations of the ‘old them’. Many participants experienced a loss of old friendships.

Charmaz (1995) spoke to the social context of changing one’s self-identity goals. The way in which people define their roles and responsibilities in relation to those around them is an important component of this process. As persons reassess previous life roles and responsibilities, they take into account several factors including their own personal desires and the perspectives and wishes of their significant others (Charmaz, 1995). People require substantial support to re-define their roles and responsibilities. In this regard, the social supports that people have to adjust with, are just as important as what they are adjusting to (Charmaz, 1995).

Charmaz (1995) also revealed a gendered component to the support of spouses. Her study found that “men did not take over tasks as readily as wives did, and they abandoned their relationships emotionally, if not completely, more quickly than women” (p.669), while wives tended to see their husbands through crises more willingly. Marriages were strained as a result of chronic illness and the loss of pivotal life roles such as breadwinner or household manager.

The literature supports the finding that stroke can result in marital and family stress for the working-aged adult (Daniel et al., 2009; Halle et al., 2011; Leys et al., 2002; Röding et al., 2003; Teasell et al., 2000; Visser-Meily et al., 2005a; Visser-Meily et al., 2005b). A study by Teasell et al. (2000) found that 38% of young stroke survivors experienced conflict with their spouse after their stroke and that 1 in 7 couples eventually separated. Leys et al. (2002) reported a 7% divorce rate as result of stroke. Also family members often take on new responsibilities which

can often result in their own needs being sacrificed and contribute to stress, anxiety and difficulty with coping (Teasell et al., 2000; Visser-Meilly et al., 2005a).

Further studies reiterated that stroke contributed to the family stress of working-aged adults (Halle et al., 2011). Family strain often occurred when stroke survivors were not able to resume pre-stroke family roles and responsibilities. Female participants, in a study by Roding et al. (2003), had been responsible for the household management and caregiving tasks of their family before their stroke and reported distress regarding their inability to resume these roles post-stroke, which contributed to family strain. Daniel et al. (2009) also reported how stroke negatively affected family dynamics and relationships through challenges such as: parent-child conflicts, the impact on children as they assume caregiver roles and troubles with child care. Stroke can affect all members of a family system. For the working-aged population, their spouses, children, and often their parents are impacted by their family member's stroke (Visser-Meily et al., 2005b).

Similar to the findings of the current study, Charmaz (1983) also revealed that social isolation often occurs as a result of chronic illness. Friendships often diminish as the person is no longer engaged in the same social worlds. The reciprocity inherent to relationships is often lost when the person with chronic illness is no longer able to contribute to the relationship in the same ways. This work also described the strain that is imposed on relationships with family and close friends, as they become worn out and experience their own suffering due to continuous immersion in their loved one's illness. Feeling a failure to live up to others' expectations also contributes to the dissolution of relationships. When persons with chronic illness return to previous social circles and become surrounded by visible symbols of their previous life, they

often felt inadequate and overwhelmed (Charmaz, 1983). This aligns with the reports of participants from the current study.

Carrying on.

The current study revealed that once participants accepted that their life as they knew it pre-stroke had changed, they began to re-define, adjust, adapt and accept who they were becoming. Prior to the stroke, most participants led highly productive and active lives; they were busy ‘doing’ all the time. Their stroke left them with residual deficits that presented a barrier to their ability to resume this type of active lifestyle. The participants described great fear, guilt, inadequacy and sadness regarding their inability to ‘do’. They also revealed the negative impact of not ‘doing’ on their self-worth, self-esteem, self-confidence and self-identity, which also impacted on their overall life satisfaction and well-being.

Participants went on to describe coming to the realization that they needed to carry-on with a life that included living with stroke and not focussed solely on working, money and ‘doing’. For some that meant having to ‘do’ differently, for others it meant completely redefining the role that ‘doing’ had played in their lives. As participants let go of their pre-stroke lives, they entered into a phase of adjustment, adaptation and redefinition. These experiences ultimately led them to a place of acceptance and from there participants transitioned to transcendence.

Studies which have examined adapting to life after stroke, have similar findings to those of the current study (Bendz, 2003; Burton, 2000; Easton, 1999; Ellis-Hill et al., 2000; Rochette, Tribble, Desrosiers, Bravo, & Bourget, 2006). Easton (1999) found that an integral component of adapting to life after stroke involved participants taking ownership and control over their recovery. Participants shifted their recovery focus of regaining their former unimpaired self to achieving a sense of normality in their life and accepting that they would not likely regain their

pre-stroke existence (Easton, 1999). One participant stated that “it took her five years to realize she was not going to recover, but once this realization occurred, she felt liberated and was able to create a ‘new normal’ for herself as a disabled person” (Easton, 1999, p.75). Rochette et al. (2006) concluded that a key element of coping after stroke is for persons to release their expectations related to resuming their previous life style and change how they perceive their current life situation, thereby achieving a level of resignation and acceptance that will allow them to achieve an optimal quality of life. Both Burton (2000) and Bendz (2003) suggested that it is more important for persons living with stroke to adapt and accept their new life situation than it is for them to recover specific functional abilities.

Ellis-Hill et al. (2000) explored the process of biographical disruption and its relation to life after stroke. Biographical disruption can be described as, “the diagnosis separating the person in the past from the person they were expecting to be in the future” (Ellis-Hill et al., 2000, p.726). Their study participants reported that the stroke had fundamentally changed their lives. They also reported experiencing an altered relationship with their bodies, something the authors described as a ‘self-body’ split. Participants experienced both existential and practical challenges with their bodies after stroke resulting in a separation of self and body (Ellis-Hill et al., 2000). They described a heightened awareness of their body after stroke; it was no longer strong and dependable. Participants strived to understand and gain control over their now unreliable and unpredictable bodies (Ellis-Hill et al., 2000). At one year post-stroke, most participants were still working on creating a clear sense of self through the negotiation and realignment of their body and self, thus trying to resolve their self-body split (Ellis-Hill et al., 2000).

Adaptation and acceptance appeared in the current study as key elements of the working-aged person's journey of surviving a stroke in the prime of their life and therefore integral components of successful community reintegration. Several models exist in the literature related to adaptation and coping with disease and impairment. For the purposes of this study I have chosen to focus on Kathy Charmaz's grounded theory related to living with chronic illness. Charmaz is an occupational therapist and sociologist as well as a leading qualitative researcher and grounded theorist who has extensively studied the effect of chronic illness on a person's self-concept (1983, 1990, 1991, 1995). Participants from the current study consistently revealed the impact their stroke had on their self-identify, therefore Charmaz's (1995) work on the role of the body, identity and self in the process of adapting to impairment is of particular interest to this study. Charmaz found that "chronic illness with impairment intrudes upon a person's daily life and undermines self and identity" (p. 657). Her findings refer to chronic illness as an assault to the body and a threat to one's integrity of self, as the chronic illness and impairment challenge previous assumptions about the person's healthy, strong body (Charmaz, 1995; Rittman Boylstein, Hinojosa, Sberna Hinojosa, & Haun, 2007).

Charmaz (1983) revealed that people experience a diminished self-concept, when their chronic illness whittles away at their former self-images at a more rapid rate than they are able to build and re-establish new, equally valued self-images. This loss of self-concept also results in a loss of self-esteem and self-worth. In addition, the frequent loss of productive functioning and the financial strain that is commonly affiliated with chronic illness, challenges the ideologies of capitalism which pervade the mainstream community, and further contribute to a devalued self for the person with a chronic illness (Charmaz, 1983). This aligns with what the participants of the current study described related to their experience after stroke.

Charmaz (1995) offered a theory related to adapting to living with impairment which is of relevance to the findings of the current study. Charmaz (1995) described adapting as “altering life and self to accommodate to physical losses and to reunify body and self accordingly... adapting implies that the individual acknowledges impairment and alters life and self in socially and personally acceptable ways...adapting shades then into acceptance” (p.657). Successful adaptation therefore requires resolution of the struggle between body and self, “successful adaptation means living with illness without living solely for it” (Charmaz, 1995, p.658). The theory of adaptation to chronic illness described by Charmaz is reflective of the experiences described by the participants of the current study as they reintegrated back into their communities and travelled the journey of surviving a stroke in the prime of their life.

Charmaz (1995) stated that adaptation involves three stages, which are similar to the findings of the current study. The first stage consists of the person experiencing an altered body, defining their impairment and making reassessments. This stage often begins with the person expecting to regain their pre-morbid body and life. As time passes, they begin to reassess and alter their perceptions of this as a reality. The second stage includes weighing the gains and losses of their new life situation and redefining their future identity accordingly. Charmaz (1995) described the difference between struggling against illness and struggling with illness. On one hand, when people struggle against their illness, they perceive their illness as the enemy whom they must defeat in order to regain their pre-morbid identity and restore their sense of self. On the other hand, people who struggle with their illness, focus on maintaining their bodily functioning and living as normal a life as possible within their given circumstances. This allows them to integrate their new bodily reality with their self-concept (Charmaz, 1995). “After making identity trade-offs, people often try to redefine their identity choices in positive ways” (Charmaz, 1995, p.671).

The third and final stage of adaptation involves surrendering to the new body and ending the struggle to control the illness, thereby unifying their body with their self (Charmaz, 1995). Surrendering in this sense is not about resigning or being overtaken without choice, it is a deliberate choice to ‘let go’ that the person makes in order to reclaim his/her illness and facilitate a unity between body and self. For many, this process of surrender includes letting go of the desire for a complete recovery, letting go of a wish to regain their former unimpaired self and essentially opening themselves up to the opportunity of transforming the self (Charmaz, 1995).

Successful adaptation results in the person transcending their chronic disease by defining themselves as much more than their disease or impairment (Charmaz, 1995). In this sense, presenting “the possibility of building new and deeper meanings of the relation between body and self...by freeing the self from a quest for control, it becomes possible to experience the moment and to allow the boundaries of the self to flow out and to expand” (Charmaz, 1995, p.674).

Transcending the stroke.

Each of the participants in the current study arrived at a place of transcending their stroke and described an element of being better now because of the stroke. While the reason for being better varied amongst the participants, the notion of rising above and achieving some form of gratitude was a common outcome.

There is a growing body of literature related to posttraumatic growth, which can be defined as “the individual’s experience of significant positive change resulting from the struggle with a major life crisis” (Calhoun, Cann, Tedeschi, & McMillan, 2000, p. 521). Although there has been increasing inquiry in the literature related to posttraumatic growth and positive reframing of severe illnesses, little is known about this process with stroke (Gillen, 2005).

Tedeschi and Calhoun (2004) described posttraumatic growth as “the experience of positive change that occurs as a result of the struggle with highly challenging life crises. It is manifested in a variety of ways, including an increased appreciation for life in general, more meaningful interpersonal relationships, an increased sense of personal strength, changed priorities, and a richer existential and spiritual life” (p.1). In order for posttraumatic growth to occur, the person has to experience a highly stressful event as a life crisis (Tedeschi & Calhoun, 2004). This experience impacts on the person's views about the world and the self and results in the re-evaluation and re-definition of their existence in light of the traumatic event. “This process of meaning-making helps the individual reach a higher level of functioning and to rebuild new goals and beliefs, resulting in the perception that one has grown through this process” (Gangstad, Norman, & Barton, 2009, p.70).

Gangstad et al. (2009) examined whether posttraumatic growth occurred after stroke and explored its association with cognitive processing and psychological distress. The sample included persons post-stroke who were engaged in or recently completed outpatient stroke rehabilitation. The study findings indicated the possibility of posttraumatic growth after stroke, as well as revealing a significant relationship between cognitive processing and stroke. This suggests that stroke rehabilitation interventions focusing on meaning-making be considered to encourage posttraumatic growth (Gangstad et al., 2009).

Gillen (2005) investigated the use of a coping strategy called ‘positive reframing’, which involves the identification of positive consequences of stroke, with an acute stroke population undergoing inpatient stroke rehabilitation. Most of the participants were able to identify at least one positive consequence of their stroke including increased health awareness, increased amount of time spent with families and friends and personal growth as experienced through a heightened

appreciation of life (Gillen, 2005). Gillen (2005) indicated that “the ability to identify positive consequences may be an underestimated adaptation to adverse life events.” (p. 348). Gillen called for further research into the mechanisms of this ability and if it is something that can be facilitated or learned as well as if this ability is associated with positive health outcomes in the stroke population.

Although none of the participants in the current study indicated that they would have chosen to have a stroke, in their own unique way, they have each transcended their stroke and have described how they have risen above it and have become better because of it.

Recommendations and Implications for Stakeholders

The implications of this study are directed at policy makers, stroke guideline developers, health system planners and stroke care providers. In order to develop appropriate and effective strategies and services to support the community reintegration and long term stroke recovery of working-aged persons post-stroke, there needs to be a call to action for the delivery of client-centered care. This call to action needs to impact the stroke care continuum: from primary care through rehabilitation, community reintegration and effecting the various layers of the health system. Starting with policy and funding legislation, stroke guideline development, stroke system planning through to stroke care delivery, attention to client centered practise needs to be addressed for change to occur.

Client centered practice includes “demonstrating respect for clients, including clients in decision making, advocating with and for clients in meeting clients’ needs, and otherwise recognizing clients’ experience and knowledge” (CAOT, 1997, p. 49). Although policies put forth by the government and healthcare institutions often call for client centered practice, the funding formulas and legislations that rule care and service delivery are often the greatest

barriers to its implementation. The current fiscal constraints on the health system render it difficult to implement client-centered principles into practice (Hasselkus, 2002; Wilcock, 2006). Likewise, a health system that is governed by a medical model's focus on illness rather than the person further contributes to the exclusion of the person from decision making and care planning (Hasselkus, 2002; Townsend, Langille & Ripley, 2003; Wilcock, 2006). Since medical science and economics drive our healthcare system, both of which can be detrimental to the delivery of client centered care, it is more important than ever to learn about the lived experiences and needs of working-aged persons post-stroke, in order to advocate for and develop meaningful, client centered rehabilitation plans and support their community reintegration needs.

Cott (2004) conducted a study in Toronto, using focus groups comprised of adults engaged in rehabilitation, to gain the clients' perspectives on the important components of client centered rehabilitation. The results of this study identified: 1) individualization of programs, 2) mutual participation with health professionals in decision-making and goal setting, 3) outcomes that are meaningful to the client, 4) sharing of information and education that is appropriate, timely and according to the client's wishes, 5) emotional support, 6) family and peer involvement, and 7) coordination and continuity across the multiple service sectors with an inclusion of participation, as important factors for effective client centered rehabilitation. The participants described client-centered rehabilitation as more than the direct relationship between the clients and their therapists: It represented a philosophy of the delivery of rehabilitation services. Participants reported the importance of therapists considering their individual potentials and strengths along with the best scientific evidence. One participant reported that "despite the therapist's 'best' available evidence from the literature, eventually I began walking independently with a cane" (Cott, 2004, p 1415).

Cott's study revealed that most participants felt that their rehabilitation was focused on physical recovery and basic self-care needs as opposed to preparing them for life in the 'real world'. "They prepare you to live in the hospital and then they discharge you to a place that you've never been" (Cott, 2004, p. 1416). Participants identified personal goals that extended beyond their physical functioning to include practical community living skills such as community mobility, participation in social relationships, home life, work and financial life, as well as learning how to cope with the emotional challenges associated with adjusting and adapting to living with a chronic disease (Cott, 2004). Similar to the participants of the current study, the participants felt that it was challenging to be active participants in goal setting and treatment planning, when their identified personal goals did not match up with the professional and program goals (Cott, 2004).

Cott's study also highlighted several other important aspects of client centered rehabilitation: 1) the importance of retaining hope throughout the rehabilitation process and not feeling as though they have been 'written off', 2) the unwillingness to share knowledge by the health care professional was identified as causing a power imbalance in the client / therapist relationship, which contributed to the obstruction of client centered care, and 3) the need for health care professionals to recognize that the client may require emotional support as they deal with the loss of familiar roles and meaningful activities. From the perspective of these participants, therapy that focused solely on impairments and activity limitations did not equate to client centered care (Cott, 2004).

Currently, there are no best practice recommendations or evidence based stroke rehabilitation interventions created specifically for working-aged adults. Based on the findings of the current study and related literature, key components of this type of intervention would include the

incorporation of targeted therapy related to practical life issues such as: childcare, household management, engagement in age-appropriate activities, return to work, relationships with children and spouses and financial issues.

There is also a need for the healthcare system and stroke care providers to better understand, assess and treat invisible deficits and support the rehabilitation of persons with ‘mild’ stroke deficits. Support and rehabilitation that address adaptation as well as the ‘invisible’ deficits such as fatigue and altered cognition and perception will therefore also be important elements of this client centered approach.

Therapy strategies which focus on meaningful activities and the resumption of important life roles as identified by the person with stroke versus the imposed goals and strategies by the healthcare providers will be imperative to creating a client-centered approach. Psychologists and social workers could provide the counselling and support required for the working-aged persons after stroke as they process the shock of their stroke, grieve the loss of their former abilities, redefine themselves and adapt and adjust to life after stroke (Morris, 2011).

The incorporation of vocational goals into stroke rehabilitation planning is significant to a client centered approach for working-aged persons post-stroke. For those who strongly desire to return to their former place of employment, having an advocate working with their employer to support their return to work, in some capacity, with suggestions for modifications if necessary would provide the support required for successful reintegration. For those who are unable to return to their previous place of employment, counselling and guidance related to alternate forms of paid work or volunteering could be helpful.

For client centered stroke care to occur, stroke care teams would need to consider the entire person and his or her life situation in order to develop relevant, age appropriate stroke

rehabilitation assessment and management plans (Bendz, 2003). This type of client centered stroke rehabilitation could support the community reintegration needs of working-aged persons after stroke, but would require stroke team members to be well versed in social, employment and disability legislation and financial support systems. It would also require an integrated team approach that extends beyond the medical and therapy team to include non-healthcare agencies such as peer support services, government and financial aid agencies, social and vocational services, counselling services and employers (Morris, 2011).

Many stroke services currently focus on the early post-stroke period and emphasize the rehabilitation of physical functioning. The majority of stroke recovery takes place in the community over the long-term and is predicated upon the resumption of important life-roles, engagement in meaningful activities and participation. Change is required in the community stroke rehabilitation service delivery model, so that it provides adequate intensity and client centered goal setting to support the community reintegration needs of working-aged persons with stroke.

Policy makers, health system planners and stroke care providers need to consider the physical, cognitive, affective and social domains of the working-aged person's stroke recovery. The developers of the UK National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2012) outlined that the needs of working-aged adults may not be met by standard stroke services (Daniel et al., 2009). They recommended that guideline developers begin to recognize and incorporate the unique needs of the working-age population into best practice guideline development (Daniel et al., 2009). The Canadian Best Practice Recommendations for Stroke Care distinguish between adult and paediatric stroke, but they do not differentiate between working-aged adults (18-65 years) and older adults (>65 years), even though the two

age groups have unique needs related to community reintegration and long term stroke recovery. Education and advocacy initiatives targeting stroke guideline developers could be helpful in heightening this awareness and facilitating the inclusion of this differentiation in the next iteration of best practice recommendations. As well, public awareness initiatives related to the prevalence and lived experience of working-aged persons post-stroke may help inform the public and facilitate increased public responsiveness, advocacy and support to this population.

A client centered approach to stroke care will ensure that the voices of working-aged persons post-stroke are heard and given priority in their rehabilitation and community reintegration planning, ensuring their needs are supported as they work to achieve optimal wellbeing, enhanced recovery and successful community reintegration. The results of this interpretive phenomenological study can assist policy makers, stroke guideline developers, health system planners and stroke care providers with: 1) understanding the meaning of community reintegration after stroke from the working-age study participants' perspectives, and (2) applying the insights arising from this understanding to policies, guidelines, services and approaches that are client-centered and sensitive to the needs of working-aged persons post-stroke.

Study Strengths and Limitations

This study's strengths are found in its rigour as was described earlier according to Lincoln and Guba (1985) in terms of credibility, transferability, confirmability, and dependability. Credibility, ensuring that the results are clearly reflective of the participants' perspectives, was accomplished through member-checking, triangulation of sources, peer debriefing and the use of direct quotations from the text. Although transferability is not the goal of interpretive phenomenology, the use of thick and rich descriptions of the findings, study context and participant data contributed to this element of the study's rigour. Confirmability, the extent to

which strategies were used to limit bias in the research, was achieved through reflexive exercises and journaling throughout the study in addition to the maintenance of an audit trail and the engagement in peer debriefing. Dependability, the consistency between the data and findings, was achieved through a clear description of the methodological processes as well as through the maintenance of an audit trail and the engagement in peer debriefing.

Interpretive phenomenology is an approach that is deeply rooted in philosophy. The depth to which I could learn the philosophical tenets of this approach was limited due to the timelines of this study and could be considered a study limitation. A more comprehensive understanding of the philosophy and original works of this methodology may have garnered further reflections and findings.

Directions for Future Research

Since there is limited research focusing specifically on the community reintegration needs of working-aged adults, there are several opportunities for further research. The intent of an interpretive phenomenological study is to develop a deeper understanding of the essence or meaning of a particular phenomenon, in this case community reintegration. The goal of a grounded theory approach is to move beyond understanding and to create a theory or model (Creswell, 2007). Leading grounded theorists such as Strauss, Corbin and Charmaz have applied grounded theory to the experience of living with chronic illness, and since there are currently no models or theories related to the experience of community reintegration for working-aged persons post-stroke this would be a nice fit methodologically as well as a natural next step for future research in this area.

Another direction for future research could be related to the measurement of community reintegration post-stroke. As was discussed earlier, the standardized outcome measures that

currently exist do not necessarily represent what community reintegration means to the person-post stroke and therefore may not be measuring this construct accurately (Salter et al., 2008; Wood et al., 2010). Through this study, I hope to contribute to the understanding of the lived experience of community reintegration for working-aged persons with stroke, which may help to inform the development of effective measurement strategies

The health policy field, could be another avenue for a further investigation into the obstacles of delivering client centred stroke care, with a focus on community stroke service delivery. The province of Ontario is currently undergoing a health funding reform, moving towards a quality based funding model that is intended to incentivize best practice, person centered stroke care. There will be considerable opportunities for future research to inform the work in this area.

Another area for consideration regarding future research would be related to the gendered perspectives of stroke recovery, healthcare consumption, community reintegration and care giving. Elements of gender differences emerged throughout this study but were not further investigated due to the guiding philosophical tenets and a methodological focus on community reintegration as the phenomenon of interest. It would be interesting to see what results are yielded through a secondary data analysis from a feminist theory standpoint.

Evidence related to stroke rehabilitation and community reintegration interventions for working-aged adults is lacking. Further research into these areas of intervention, including the effectiveness of peer support and vocational rehabilitation would be helpful.

Conclusion

The working-age population post-stroke, regardless of their residual deficits, have unique needs and the application of assessment and management approaches that are geared to older persons post stroke are inappropriate (Mahon et al., 2012). Since their life situations and

recovery processes differ from older adults, consideration should be given to the specific needs of this population when planning rehabilitation and supporting community reintegration in order to ensure client-centered care and service delivery (Teasell et al., 2000).

The phenomenon of interest for this study, community reintegration, was defined as “the reorganization of physical, psychological and social characteristics so that an individual can resume well-adjusted living after incapacitating illness or trauma” (Wood-Dauphinee & Williams, 1987, p.493). This definition focuses on “the ability to function, to do what one wants to do or feels one has to do, not that one must be free of symptoms, disability or help in the form of human assistance or mechanical devices. Symptoms and disability can be tolerated as long as the individual can accomplish what one wishes to do to his own satisfaction” (Wood-Dauphinee & Williams, 1987, p.493). Studies have shown that successful community reintegration, including the ability to return to an acceptable lifestyle, and participate in both social and domestic activities are important indicators of patient satisfaction and perceived quality of life post stroke (Clark & Smith, 1999; Jaracz & Kozubski, 2003; Kim et al., 1999; Mayo et al., 2002; Salter et al., 2012). Studies have also shown that persons with stroke, living in the community, and their families continue to struggle with community reintegration and find it difficult to regain a good quality of life post stroke (McKevitt et al., 2004; Reed et al., 2012; Teasell et al., 2003). Since the majority of stroke recovery takes place in the community, it is an important area to address.

The essence of the phenomenon of community reintegration for working-age persons post-stroke emerged as: The journey of surviving a stroke in the prime of your life. The six themes described throughout this thesis emerged to support this journey of community reintegration after stroke and are reflected in the overarching theme of “Life Goes On”. While participants

experienced their personal journey to community reintegration in a unique way, their journey led them to realize that in order to successfully reintegrate back into their community, they needed to adjust, adapt and reach some level of acceptance in order to move on and essentially transcend their stroke.

It is hoped that the results of this interpretive phenomenological study can assist policy makers, stroke guideline developers, health system planners and stroke care providers with: 1) understanding the meaning of community reintegration after stroke from the working-age study participants' perspectives, and 2) applying the insights arising from this understanding to policies, guidelines, services and approaches that are client-centered and sensitive to the needs of working-aged persons post-stroke.

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Thinking about your social network, do you have social supports that you are close to...e.g...feel at ease with, can talk to about private matters, or can call on for help?

Who? (e.g. sister, child, etc.)	Where do they live?

10) Employment Status:

Before the Stroke	F/T	P/T	After the Stroke	F/T	P/T

11) Socioeconomic Status:

Taking all sources of income into consideration, please estimate the total family income:

- A – less than \$19,999**
- B - \$20,000 to \$39,999**
- C - \$40,000 to \$59,999**
- D - \$60,000 to \$99,999**
- E - \$100,000 or more**

Thinking about your financial situation, would you say that you are:

- A – Having difficulty making ends meet?**
- B – Have just enough to get along?**
- C – Are Comfortable?**

Appendix B

Participant Study Information Form



Participant Study Information Form

“Exploring the experience of community reintegration for working-aged persons after stroke”

Investigators:

Local Principal Investigator:

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Introduction:

You are being invited to participate in a research project called “An exploration into the experience of community reintegration for working-aged persons post-stroke”. While research has been done on community reintegration after stroke, it has focused on older adults. Little is known about the community reintegration experiences of working-aged persons after stroke. This study wants to better understand your feelings, beliefs and thoughts about your experience after you left the hospital and reintegrated back into your life at home in the community after your stroke.

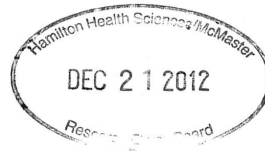
Rebecca Fleck is conducting this study as part of her Master’s Program in Rehabilitation Science in the Faculty of Health Sciences at McMaster University under the supervision of Dr. Julie Richardson, PT, School of Rehabilitation Sciences, McMaster University.

Purpose of the Study:

This study will seek to understand the lived experience of community reintegration for working-aged persons with stroke in order to widen the knowledge base on this matter and contribute to the development of appropriate and effective strategies and services to support working aged persons with stroke with their community reintegration and long term stroke recovery.

What will happen during the study?

The study will involve an interview of about one hour with Rebecca Fleck. The interview will take place at a time and location that is convenient for you. You will receive a copy of the interview questions in advance of the interview. Interview questions will be related to your stroke and your experience integrating back home and into your community after the stroke. The interview will be recorded so that your comments may be transcribed accurately. You may be contacted again to clarify anything that you said and to make sure that what you said was understood correctly.



Are there any risks to doing the study?

Interview questions will be related to your stroke, recovery and reintegrating back home into your community after the stroke therefore, the interview questions could cause you discomfort or distress as you reflect back on your experiences. A copy of the interview questions will be shared with you in advance so that you are aware of the types of questions that will be asked during the interview. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You can stop taking part in the interview or the study at any time.

Are there any benefits to doing the study?

The research will not benefit you directly. We hope to learn more about that the unique experience of community reintegration for working-aged persons after stroke. This could help inform the development of appropriate and effective strategies and services to better support the community reintegration and long term stroke recovery needs of working aged persons after stroke.

Confidentiality:

You are participating in this study confidentially. I will not use your name or any information that will allow you to be identified. No one but my supervisor, Julie Richardson and I will know whether you participated unless you choose to tell them. The information that you provide will be kept in a locked cabinet where only I will have access to it. Information kept on a computer will be protected by a password. Information will be kept on file for ten years after the study is over. Although I will protect your privacy as outline above, if the law requires it, I will be required to reveal it.

What if I change my mind about being in the study?

Your participation in this study is voluntary. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. You will have the option of removing your data from the study OR information provided up to the point where you withdraw will be kept unless you ask that it be removed. If you do not want to answer some of the questions you do not have to, but you can still be in the study. Your decision whether or not to be part of the study will not change or stop the way you use services at Hamilton Health Sciences or the Les Chater YMCA.

How do I find out what was learned in this study?

I expect to have this study completed by approximately January 2013. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study:

If you have any questions or need more information about the study itself, please contact us at:

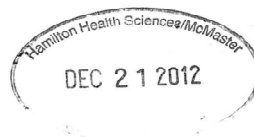
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Thank you,

Rebecca Fleck OT Reg. (Ont.)

Version Date: December 4, 2012



Page 2 of 3

Appendix D

First Interview Guide

Background:

First I am interested in hearing about your life before the stroke:

1) How would you describe yourself before the stroke?

(Probes: What sort of person would say that you were? What were you like as a person? How did you think of yourself? Can you think of anything else? How would others describe you?)

2) Were you working before you had the stroke?

(Probes: What did you do for work? How many hours a week did you work? What was your work environment like? What were your colleagues like? What were your relationships like with your colleagues? Did you spend time with them outside of work?)

3) What did work mean to you? (If applicable)

(Probes: What was its role in your life? What did you enjoy about work? What did you not enjoy about work? Did your job satisfy you? How did it satisfy you? (routine, income, productivity, link to society, satisfaction, etc.)

4) Can you describe what your family life was like before you had the stroke?

(Probes: What did your role involve as a spouse? What did your role involve as a parent? What were your responsibilities around the home? What did your role involve as an extended family member? (e.g. sister/brother; daughter/son; aunt/uncle))

5) Did you have any other major responsibilities before the stroke?

(Probes: Were you a primary or secondary caregiver to parents, siblings, friends, neighbours, etc? Were you responsible for any pets? Any volunteering or committees?)

6) What did a typical week look like before you had the stroke?

(Probes: What did your work week look like? What did your weekend look like? What were your extracurricular or leisure activities? (e.g sports, reading, active, sedentary) What was your favourite part of the week?)

7) What did a typical day look like before you had the stroke?

(Probes: What were you responsible for in a week/weekend day? What did you enjoy most about your week/weekend day? What was your favourite part of the week/weekend day?)

8) What did your social life look like before the stroke?

(Probes: What were your relationships like with others? How much time did spend socializing? (eg. with family, friends, colleagues, sports teams, etc.)

9) What gave you pleasure before your stroke?

(Probes: Favourite places, people, activities, things?)

Stroke Experience:

Now I am interested in hearing about what happened with the stroke:

10) When did you have the stroke?

11) How did you know that you were having a stroke?

12) What happened when you realized that you were having a stroke?

13) How have you been affected by your stroke?

(Probes: Did you have any physical changes? ..Any changes in your energy level? Did you have any cognitive or perceptual changes? Any changes to your thinking or memory? Any changes to your vision? Did you have any changes in your mood? Any changes with your communication? Any pain? Any fatigue?)

Community Reintegration Experience:

Now I am interested in hearing about your experience after you left the hospital and reintegrated back into your life at home in the community:

14) How long have you been home now?

15) What was it like leaving the hospital and going home for the first time since your stroke?

(Probes: What was it like for you? How did you adjust? What was it like for your family?)

16) Are you back to work? (If applicable)

(Probes if **not** back to work: How do you feel about not working? Do you want to get back to working? Why are you not back to work yet? Do you miss anything about not working? (people, relationships, routine, income, job itself, etc))

(Probes if back to work: What was the experience of returning to work like? Have you had to make any modifications to your work? Are there any differences between what work was like before the stroke versus now? Are there any differences between what work meant to you before the stroke and what it means to you now?)

17) Can you describe what your family life is like since you've had the stroke?

(Probes: Any changes to your role as a spouse? Any changes to your role as a parent? Any changes to your responsibilities around the home? Any changes to your role as a sister/brother; daughter/son; aunt/uncle? How do you feel about these changes?)

18) Have you been able to assume your other major responsibilities since you've had the stroke? (Probes: Is it different from before? Why or why not?)

19) What does a typical week look like for you now?

(Probes: Has this changed since your first few weeks home? How has it changed? Have your responsibilities changed? Have the things that give you pleasure changed? What is your favourite part of the week now?)

20) What does a typical day look like for you now?

(Probes: Where do you spend most of your time? How do you spend most of your time? Has this changed since your first few weeks home? How has it changed? Have your responsibilities changed? Have the things that give you pleasure changed? What is your favourite part of the day now?)

21) Are you able to do everything that you want to do in a day?

(Probes: What aren't you able to do it?)

22) Are you able to do everything that you feel that you need to do in a day?

(Probes: What aren't you able to do it?)

23) Have your relationships with others changed since the stroke?

(Probes: Which relationships have changed? (e.g. immediate family, extended family, friends, colleagues) Why have they changed? How does this make you feel?)

24) What does your social life look like now?

(Probes: Has it changed since the stroke? How has it changed? How do you feel about that?)

25) How do you feel about your experience reintegrating back into your life at home in the community after the stroke? (Probes: Was it better or worse than you expected? Why?)

26) What has been the easiest part of reintegrating back into your life at home in the community after the stroke?

27) What has been the hardest part of reintegrating back into your life at home in the community after the stroke?

28) Do you have any concerns about life right now?

(Probes: related to life after stroke?)

29) Do you have any concerns for the future?

(Probes: related to life after stroke?)

30) What do you look forward to now?

Community Supports & Services:

31) What services or supports did you find helpful in supporting your community reintegration? (Probes: How did you find out about those services? How did you connect with those services? Did you have help navigating the system?)

32) Were there any services or supports that you did NOT find helpful in supporting your community reintegration? (Probes: What were they? Why did you not find them helpful?)

33) What additional services or supports would be helpful in supporting you now?
(Probes: Has this changed since you first returned home? How has it changed? Are there services that exist but you were not able to access? Are there services that do not exist that might have been helpful?)

34) How would you describe the gaps in the system for supporting working-aged persons with stroke to re-integrate back into their communities?

Wrap-Up:

35) What advice would you give to a working-aged person that has recently had a stroke?
(Probes: related to reintegrating back into the community)

36) Is there anything else that I have not asked you that you think is important?

Thank you for taking the time to participate in this study. Can I contact you at a later date for a second interview or clarification of interview material?

Yes

No

Appendix E

First Advance Interview Guide for Participants

Background Questions:

First I will be asking you some questions about your life before the stroke:

- What did a typical week look like before you had the stroke?
- What did a typical day look like before you had the stroke?

Stroke Experience:

Then I will ask you some questions about what happened with the stroke:

- When did you have the stroke?
- How did you know that you were having a stroke?
- What happened when you realized that you were having a stroke?
- How have you been affected by your stroke?

Returning Home After the Stroke:

Then I will ask you some questions about your experience after you left the hospital and reintegrated back into your life at home in the community:

- What was it like leaving the hospital and going home for the first time after your stroke?
- If you were working before the stroke, are you back to work now?
- Can you describe what your family life is like since you've had the stroke?
- What does a typical week look like for you now?
- What does a typical day look like for you now?
- What services or supports did you find helpful in supporting your community reintegration?
- What services or supports did you find to be missing, that could have helped to support you?

Appendix F

Final Interview Guide & Final Advanced Interview Guide for Participants

Background:

1) How would you describe yourself before the stroke?

(Probes: What were you like as a person? How did you think of yourself? Can you think of anything else? How would others describe you?)

Stroke Experience:

2) When did you have the stroke?

3) How did you know that you were having a stroke?

4) What happened when you realized that you were having a stroke?

5) What are the most significant ways that you have been affected by your stroke?

(Probes: Did you have any physical changes? ..Any changes in your energy level? Did you have any cognitive or perceptual changes? Any changes to your thinking or memory? Any changes to your vision? Did you have any changes in your mood? Any changes with your communication? Any pain? Any fatigue?)

Community Reintegration Experience:

6) How long have you been home now?

7) What was it like leaving the hospital and going home for the first time since your stroke?

(Probes: What was it like for you? How did you adjust? What was it like for your family?)

Work:

8) Were you working before you had the stroke?

If yes, can you tell me about your work life?

(Probes: What did you do for work? How many hours a week did you work? What was your work environment like? What were your colleagues like? What were your relationships like with your colleagues? Did you spend time with them outside of work?)

9) Can you tell me what work meant to you? (If applicable)

(Probes: What was its role in your life? What did you enjoy about work? What did you not enjoy about work? Did your job satisfy you? How did it satisfy you? (routine, income, productivity, link to society, satisfaction, etc.)

10) Are you back to work now? (If applicable)

(Probes if **not** back to work: How do you feel about not working? Do you want to get back to working? Why are you not back to work yet? Do you miss anything about not working? (people, relationships, routine, income, job itself, etc))

(Probes if back to work: What was the experience of returning to work like? Have you had to make any modifications to your work? Are there any differences between what work was like before the stroke versus now? Are there any differences between what work meant to you before the stroke and what it means to you now?)

Family:**11) Can you describe what your family life was like before you had the stroke?**

(Probes: What did your role involve as a spouse? What did your role involve as a parent? What were your responsibilities around the home / outside of the home? What did your role involve as an extended family member? (e.g. sister/brother; daughter/son; aunt/uncle))

12) Can you tell me what your family life has been like since you've had the stroke?

(Probes: Any changes to your role as a spouse? Any changes to your role as a parent? Any changes to your responsibilities around the home / outside of the home? Any changes to your role as a sister/brother; daughter/son; aunt/uncle? How do you feel about these changes?)

Other Responsibilities:**13) Did you have any other major responsibilities before the stroke?**

(Probes: Were you a primary or secondary caregiver to parents, siblings, friends, neighbours, etc? Were you responsible for any pets? Any volunteering or committees?)

14) Have you been able to resume your other major responsibilities since you've had the stroke? (Probes: Is it different from before? Why or why not?)**15) How do you feel about your experience reintegrating back into your life at home in the community after the stroke? (Probes: Was it better or worse than you expected? Why?)****16) What has been the easiest part of reintegrating back into your life at home in the community after the stroke?****17) What has been the hardest part of reintegrating back into your life at home in the community after the stroke?****18) Are you able to do everything that you want to do in a day?**

(Probes: What aren't you able to do it? Can you describe that for me....)

19) Are you able to do everything that you feel that you need to do in a day?

(Probes: What aren't you able to do it? Can you tell me more about that....)

20) Have your relationships with others changed since the stroke?

(Probes: Which relationships have changed? (e.g. immediate family, extended family, friends, colleagues) Why have they changed? How does this make you feel?)

Future:

Looking ahead towards the future:

21) What are the things that you have concerns about?

(Probes: related to life after stroke?)

22) What are the things that you look forward to?

(Probes: related to life after stroke?)

Wrap-Up:

23) What advice would you give to a working-aged person that has recently had a stroke?

(Probes: related to reintegrating back into the community)

24) Is there anything else that I have not asked you that you think is important?

Thank you for taking the time to participate in this study. Can I contact you at a later date for a second interview or clarification of interview material?

Yes

No

Appendix G

Analysis Step # 1 – Sample of Holistic Approach

Isolating Thematic Statements:

1) The wholistic or sententious approach: Where you attend to the text as a whole and ask “*What sententious phrase may capture the fundamental meaning or main significance of the text as a whole?*” Then try to express that meaning by formulating such a phrase.

This involved reading the entire transcript to grasp its overall meaning.

Each transcript was summarized to reflect the overall meaning of the interview.

Transcript	Summary	Sententious Phrase
P001	<p>A young single mother who is accustomed to being very independent and living a very busy and active life caring for her son, helping with her dad and nephew, managing her home, working and being very physically active. She describes the struggle of ‘trying to do it all’ as a single mother – once she had her son she wasn’t able to sit on every committee and coach every team – she felt very guilty about this. She attributes stress as causing her stroke. She describes fatigue, depression and cognitive deficits as the biggest barriers to her daily functioning and recovery post stroke. She also perceives a temporal component to her recovery: the early days were focused on her recovery with lots of support and lots of progress – this transitions to more of a focus on resuming daily life and redefining yourself with less support and less progress. She talks a lot about the challenge of ‘invisible’ deficits and how nobody else understands or notices and so this contributes to a sense of feeling ‘alone’ in your recovery and day to day life. Returning to the role of single parent and household manager is currently a challenge and returning to work – ‘to doing it all’ – is not currently possible. She struggles with feelings of guilt and inadequacy – which seem to stem from her own adjustment to her new self and ‘not being able to do it all’ anymore – as well as her perception that others are also not understanding / judging her. She feels a strong need for others to understand her and what is going on. She also describes the importance of having breaks/nothing time...essentially ‘being’ time built into every day and I think struggles with society not perceiving that as productive? She describes expectation management related to recovery and day to day functioning and appears to be striving for ‘normalcy’ in her life – although I don’t think that she knows what ‘normal’ means now. Clear grieving over the loss of her previous self. Clear example of the importance of ‘being’ during recovery.</p>	“Nobody Understands”

Appendix H

“Who Am I?” Exercise

Who Am I As a Researcher?

The thing that I am most excited about in my study is having the opportunity to actually sit down and spend time with the participants that I will be interviewing to hear their stories and get their perspectives. The healthcare system within which I work is so busy and hectic that rarely do we have the opportunity to spend sufficient time with people to form a real therapeutic rapport and hear their personal stories. Learning about people is something that I get huge satisfaction out of and I am really looking forward to spending time with the participants and hearing about their experiences and perceptions, in detail.

My main hope for this study is to be able to better understand what community reintegration means to working-age persons after stroke and to discover what impact it has in their day to day life experiences. My next hope will be to effectively share this understanding with other healthcare providers to contribute to a more meaningful, client centered approach to community stroke care service delivery.

There are two main things that I am afraid of about doing this study, and they both involve the interview process. The first is a fear of not allowing for sufficient silence during the interview. I am not typically comfortable with silence during a conversation, but recognize that this may be an important part of the interview process. So, need to ensure that I give the participants time to think and reflect. The second fear is that my quantitative, evidence based, healthcare professional ‘hat’ will somehow contaminate the qualitative research methodology process by my innate desire to have literature, evidence and theory guiding my practice. In other words I get comfort out of predictability and control, both of which will be counterproductive to the interpretive phenomenological approach, so I will need to work very hard at keeping that in check.

The biggest assumption I am making about what I expect to learn in the study is that there will be gender differences discovered in the meaning of community reintegration with my participants. Initially, my research question would have been more along the lines of: “What are the gender differences in community reintegration for working-age persons post-stroke?”. I have realized that this assumption is unclear at the present time and that my goal is to discover the meaning of community reintegration, without preconceived assumptions of difference.

The main way that this research draws on my own experience is that I am an occupational therapist, currently working as the Central South Regional Stroke Education and Research Coordinator with experience related to community reintegration and transition management with stroke care providers, individuals with stroke and their families.

The one thing I am sure of when starting the research is that I am very eager to start hearing people’s stories and gathering data. I would be really surprised if, as a result of the research, I learned that participants do not experience challenges related to community reintegration.

Why Do I Want To Do This Study?

Personally and professionally, I have a passion for stroke. I have been working in the field of stroke care for over 10 years, so am very aware of the large numbers of people that are living with the effects of stroke in our community. I am also aware that reintegrating back into the community is consistently reported by stroke survivors and their families to be a stressful and challenging time (Lindsay et al., 2010). I am interested in better understanding what community reintegration actually means to working-age persons living with stroke. I am hoping that this understanding will inform the knowledge base related to community reintegration after stroke as well as provide a greater understanding of the unique life situation of working-age persons with stroke in order to contribute to a more meaningful, client centered approach to care delivery.

I have already briefly spoken about my healthcare professional, occupational therapist, and regional stroke educator ‘hats’. I have several other ‘hats’ that might influence me as a researcher. My most important role in life is that I am a mother to my almost five year old daughter. My ability to care, love, and empathize has been exponentially magnified since having my daughter. Becoming a mother seems to have enhanced my ability to ‘feel’ in general and so I think that this will impact on my research in that I will be very empathetic to my participants.

I am also a wife, sister, daughter and granddaughter. Over the past few years, these roles have really taught me a lot about how much I value supportive relationships in my life. I have also learned a lot about being a caregiver. As my grandparents have aged, I have learned through them a lot about dementia and stroke and living with chronic disease, from the family member or caregiver perspective. I have also recently been a patient myself in the hospital. Through these experiences, I have developed opinions and biases related to the service delivery (or sometimes lack thereof) of our healthcare, long term care and community care systems. I am very aware of bringing these perceptions and biases to my research and need to utilize this awareness as I move towards the process of properly integrating these perceptions into my research.

A common thread with all of these ‘hats’ is also my nature to want to help. When someone has a problem, I want to help them solve it. I have come to learn that sometimes people really want and appreciate your assistance, but others times they may just want you to listen. As a mother I have learned that this is a necessary step in teaching my daughter how to solve problems on her own. I need to be aware that I will be interviewing participants to learn more about their experience. I need to be intentional with my attentive listening and not become distracted by my desire to want to help.

This exercise has been an important first step in bringing awareness to how my life roles, values, assumptions and biases could influence my study. I will need to continue to reflect on this throughout the study process, and learn how to integrate these components into my interpretive phenomenological approach.

Appendix I

HHS/FHS REB: Student Research Committee Final Approval Letter



HHS/FHS REB: Student Research Committee

Final Approval

Date:	December 21, 2012
REB Number:	12-703-S
Title of Study:	An exploration into the experience of community reintegration for working-aged persons post-stroke following an interpretive phenomenology approach
Student PI:	Rebecca Fleck
LPI:	J. Richardson
Version date:	Document:
Dec 4 2012	Application
Dec 4 2012	Protocol
Dec 4 2012	Information and Consent Form
Dec 4 2012	Email Script/Telephone Script
Dec 4 2012	Interview Guide

Dear Rebecca:

We have completed our review of your study and are pleased to issue our final approval. You may now begin your study.

All recruitment and consent material must bear an REB stamp.

Any changes to this study must be submitted as an amendment before they can be implemented. Amendment forms are available on our website.

This approval is effective for 12 months from the date of this letter. If you require more time to complete your study you must request an extension in writing before this approval expires. Please submit an Annual review form with your request.

Please cite the REB number in any correspondence.

Good luck with your research,

Kristina Trim, PhD, RSW
 Chair, HHS/FHS Student Research Committee
 Health Research Services, HSC 1B7, McMaster University

The HHS/FHS SRC complies with the guidelines set by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans and with ICH Good Clinical Practice.

