FAMILY CAREGIVERS’ EXPERIENCES WITH STROKE SURVIVORS WEEKEND HOME PASSES FROM IN-PATIENT REHABILITATION

by

Amanda M. Marsella

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

© Copyright by Amanda M. Marsella (2009)
Family Caregivers’ Experiences with Stroke Survivors’ Weekend Passes from In-Patient Rehabilitation

Master of Science (2009)

Amanda M. Marsella

Graduate Department of Rehabilitation Science, University of Toronto

Abstract

This qualitative study investigated the experiences of family caregivers who cared for a stroke survivor throughout weekend passes from an in-patient rehabilitation facility. Following a Husserlian phenomenological perspective, I interviewed 15 family caregivers of stroke survivors on two separate occasions: within one week after their first scheduled weekend pass, and again two weeks after their final transition home. Interviews followed a semi-structured interview guide, and were audio recorded. Interviews were transcribed verbatim, and analyzed using the principles outlined by Giorgi (1997). Analysis of the caregivers’ descriptions of their experiences led to five themes: (i) Caregivers feel overwhelmed throughout the weekend pass, (ii) Access to supportive resources influences caregiving experiences, (iii) Caregivers adjust to the weekend pass throughout its subsequent use, (iv) Caregivers feel a responsibility and a need to be included by health professionals in the care of their family stroke survivor, and (v) Caregivers describe the weekend pass as a means towards recovery. This study has implications for future health services. By appropriately training and supporting caregivers throughout the weekend pass health care professionals can increase the positive experiences of caregivers, and optimize the opportunity to prepare caregivers and stroke survivors for the eventual transition home.
Acknowledgements

I would first like to extend my sincerest thanks to my supervisor Dr. Jill Cameron for her constant support and encouragement throughout this research process. I will be forever indebted for her advice and her investment both in this project and in my own personal growth. I would also like to thank my supervisor Dr. Judith Friedland for her heartfelt guidance and for always reminding me what the essence of this project was really about. I would also like to extend great gratitude to Dr. Denyse Richardson, for her devotion to this project, and to my success as a student. Thank you to the staff at the rehabilitation facility for their generous help and support throughout this process. Thank you also to the rehabilitation facility for providing a student scholarship in support of me as a researcher, as well the Ontario Stroke System who contributed a research grant in support of the study.

Thank to you my supportive family and friends for their patience and invaluable feedback on this project and my experiences. It is because of them that I made it through this emotional journey.

Finally, a very special thank you to the caregivers who took the time out of their busy schedules to shine light on the weekend pass experience. It is through their devotion that this study became a reality.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>PREAMBLE</td>
<td>1</td>
</tr>
<tr>
<td>GLOSSARY</td>
<td>3</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>4</td>
</tr>
<tr>
<td>1.1 Transitions in Healthcare</td>
<td>4</td>
</tr>
<tr>
<td>1.2 Stroke and Transitions</td>
<td>6</td>
</tr>
<tr>
<td>1.3 Transitioning Home to the Family Caregiver</td>
<td>9</td>
</tr>
<tr>
<td>1.4 Overview of Stroke Rehabilitation in Ontario</td>
<td>13</td>
</tr>
<tr>
<td>1.4.1 Weekend Home Passes</td>
<td>16</td>
</tr>
<tr>
<td>1.4.2 Weekend Pass Process and Potential Benefits</td>
<td>16</td>
</tr>
<tr>
<td>1.4.3 The Existing Problem</td>
<td>19</td>
</tr>
<tr>
<td>OBJECTIVES</td>
<td>23</td>
</tr>
<tr>
<td>METHODOLOGY</td>
<td>24</td>
</tr>
<tr>
<td>2.1 Introduction</td>
<td>24</td>
</tr>
<tr>
<td>2.2 Exploring the Method of Inquiry</td>
<td>25</td>
</tr>
<tr>
<td>2.2.1 The Philosophical Phenomenological Movement</td>
<td>26</td>
</tr>
<tr>
<td>2.2.2 Phenomenology as a Methodological Approach</td>
<td>30</td>
</tr>
<tr>
<td>2.3 Application to the Method of Inquiry</td>
<td>33</td>
</tr>
<tr>
<td>2.3.1 My Philosophical Orientation</td>
<td>33</td>
</tr>
<tr>
<td>2.3.2 My Methodological Approach</td>
<td>34</td>
</tr>
</tbody>
</table>
2.4 The Research Protocol
   2.41 Research Design
   2.42 Data Collection
   2.43 The Investigator’s Assumptions
   2.44 Research Participants
   2.45 Data Analysis
   2.46 Acknowledging Limitations and Increasing Rigor

2.5 Summary

MANUSCRIPT
   3.1 Abstract
   3.2 Introduction
   3.3 Purpose
   3.4 Methods
      3.41 Orientation
      3.42 Study Design
      3.43 Participants
      3.44 Data Analysis
   3.5 Results
      3.51 Participants
      3.52 Findings
   3.6 Discussion
## LIST OF TABLES

<table>
<thead>
<tr>
<th>Table Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>TABLE 1: Weekend Pass Literature</td>
<td>22</td>
</tr>
<tr>
<td>MANUSCRIPT TABLE 1: Sample Interview Questions</td>
<td>52</td>
</tr>
<tr>
<td>MANUSCRIPT TABLE 2: Clinical Messages</td>
<td>84</td>
</tr>
</tbody>
</table>
LIST OF FIGURES

FIGURE 1: Placement of Weekend Passes 18
FIGURE 2: Comparative Phenomenological Approaches 31
MANUSCRIPT FIGURE 1: The Phenomenon of the Weekend Pass Caregiving Experience 74
## LIST OF APPENDICES

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Caregiver Interview Guide</td>
<td>107</td>
</tr>
<tr>
<td>B</td>
<td>Letter of Ethics Approval</td>
<td>112</td>
</tr>
<tr>
<td>C</td>
<td>Caregiver Consent Form</td>
<td>114</td>
</tr>
</tbody>
</table>
PREAMBLE

The point of discharge from a hospital setting to the home environment is a difficult and stressful time for many patients and their families. Patients and caregivers are frequently under-prepared for what transpires after hospital discharge, and what their respective roles are in the process (Coleman, Mahoney, & Parry, 2005). Consequently, such individuals may experience poor psychosocial and psychological outcomes during this transitional period (Turner, Fleming, Cornwell, Worrall, Ownsworth, Haines, Kendall, & Chenoweth, 2007), and this may negatively influence the stroke survivors’ recovery, and threaten the sustainability of life in the home (Frazen-Dahlin, Larson, Murray, Wredling, & Billing, 2007). This is particularly true of patients who have been hospitalized for an extended period of time, often due to their complex illnesses and breadth of associated issues they face (Turner, Fleming, Ownsworth, & Cornwell, 2008). In particular, clients of rehabilitation services (such as stroke survivors) traditionally experience longer hospital stays and often face residual disabilities. Rehabilitation literature has recognized that discharge from a rehabilitation setting is a deeply disconcerting time for patients and their family caregivers (Cott, Wiles, & Devitt, 2007).

In response, community reintegration has become a popular outcome variable in rehabilitation research (Turner et al., 2008, p. 1153). However, the majority of this literature is focused on the long term outcomes of rehabilitation (greater than 2 years) as opposed to the initial transition period from the rehabilitation facility to the home itself (Turner et al., 2008). Often overlooked, this transition period encompasses some of the greatest challenges facing patients, caregivers, clinicians, and rehabilitation scientists. In
a recent study, rehabilitation clients voiced a need for further support and information around the transition from hospital to home (Cott, 2004). However, little research has been conducted on this particular transition period, and thus, little is known of the experiences of stroke survivors and their family caregivers during this time. Consequently, families are often poorly prepared and lack the information and skills they need for a successful recovery (Brereton, 1997). With decreasing support services offered in the community, an ever-aging population, and an increasing incidence of stroke, the time to explore the experiences of stroke survivors and their caregivers in transition is now.

To help address these issues, the following thesis will review the existing literature surrounding the transitional experiences of stroke survivors and family caregivers. This project will also add to the existing literature in this area by gathering the experiences and perceptions of family caregivers undertaking weekend passes. Due to the overall lack of existing literature surrounding weekend passes, articles with complimentary focuses will also be presented. This will include extending our review to relevant areas including searching peer-reviewed literature pertaining to broader transitions (such as those into rehabilitation and other health care settings), along with literature pertaining to the general experiences and needs of stroke family caregivers, and caregivers at large. From this review, a better understand of the transitional experiences of caregivers throughout a weekend pass will be uncovered.
GLOSSARY OF TERMS

**Complicated Transitions:** A movement from a less intense to a more intense care setting (e.g. home back to the hospital). Such transitions may signify potential health system failures and/or an improper initial discharge.

**Family Caregiver:** The person primarily responsible for providing and/or coordinating stroke survivor care in the community, without financial compensation. A family caregiver may be a friend or relative of the patient.

**Stroke Survivor:** A person who has endured a stroke (irrespective of the type or location in brain), who may suffer residual physical impairments, cognitive impairments, behavior changes, and/or difficulty performing activities of daily living.

**Weekend Pass:** A leave granted to rehabilitation in-patients, which allows patients to return home for the weekend (including overnights). Patients generally leave the rehabilitation facility on Friday evening and return Sunday evening. While at home they are looked after by their family caregiver.
CHAPTER 1

INTRODUCTION

1.1 Transitions in Healthcare

As today’s healthcare system moves towards increased specialization, it is
becoming all the more rare for any one clinician, or even any one facility, to manage a
patient’s care from start to finish. As a result, patient transitions between care settings
have become frequent, and unavoidable. Patients and their families who find themselves
entering inpatient care for the first time, may be surprised by the number of transitions
they experience as they navigate their way through an increasingly complex health care
system (Arora & Farnan, 2008). In a 1994 US National Long-Term Care Survey,
researchers found that throughout a 2-year period there were over 15 million transitions
within a 5-million-person sample. In addition, over 9% of survey respondents reported
experiencing seven or more transitions throughout their care (Boling, 2009). Such
transitions will only increase in regularity and importance in the coming years as our
population ages and our healthcare system moves further towards such specialization
(Cotter, Smith, & Boling, 2002).

Whenever a transition in care occurs, the goal is a seamless and safe movement
from one setting to the next. Executing effective transitions across care settings can be
challenging, however, due to the often rapid nature of a patients’ discharge coupled with
the number of individuals involved (such as the patient and family, the discharging
medical team, a discharge planner, as well as multiple post-discharge care and service
Poor quality transitions of care have become an increasing problem in healthcare systems across the world (Coleman et al., 2005; Cotter et al., 2002). Boling (2009) reports that there are identifiable problems with more than 50% of the transitions that occur between care settings. Many of these issues stem from avoidable problems such as lack of communication and deficient coordination of care (Arora & Farnan, 2008). Such issues may generate problematic transitions, which ultimately lead to conflicting recommendations regarding medications, duplications in care, lack of follow-up care, a delay in treatment, and increased rates of re-hospitalization (Coleman & Berenson, 2004; Cotter et al., 2002). Increasingly, evidence indicates that both patient safety and quality of care are jeopardized for patients in transition.

Quantitative research has identified some of the problems associated with poor post-hospital transitions including unstable vital signs, care-errors and discrepancies, and health relapses (Coleman et al., 2005). Qualitative investigations involving patients and their caregivers who have recently transitioned has revealed common themes, including significant anxiety, lack of understanding, a sense of abandonment, and feelings of overall disregard for their preferences or input in the design of their care plans (Coleman et al., 2005). As much as 15 to 25 percent of all patients in transition may experience such adverse consequences (Boling, 2009).

Transitions in care are clearly a precarious time with much at stake. Yet, despite the obvious need to reduce fragmented transitions, very little effort has been made to assist patients and family members in transition (Coleman & Berenson, 2004). Furthermore, very little research exists discussing transitions in care, and the appropriate
way to render such complicated issues. In 2008, a rare qualitative systematic review was conducted discussing factors contributing to a successful transition to community based care for adults with chronic needs (Jacob & Poletick, 2008). The reviewers noted a paucity of available information, and as result, were only able to identify ten articles for review (from 1987 to 2007). From their investigation, however, Jacob and Poletick (2008) noticed one particular population was most susceptible to complicated transitions: stroke survivors and their family caregivers. The reviewers found that stroke survivors and their family caregivers were at the highest risk of facing fragmented transitions throughout their care, an outcome which is likely due to their increased age, length of hospital stays, and presence of residual impairments.

1.2 Stroke and Transitions

Stroke is the fourth leading cause of death and a leading cause of long-term disability in Canada (Health Canada, 2000). Stroke is also the leading cause of adult neurological disability in Canada, with over 300,000 people living with its consequences (Teasell, Foley, Salter, & Jutai, 2008). According to our calculation, that means 4.1% of all Canadians over the age of 65 are stroke survivors. The effects of stroke are so widespread that survivors of stroke make up the largest group of patients admitted to rehabilitation facilities (Kind, Smith, Frytak, & Finch, 2007). The direct cost of stroke to the Canadian healthcare system is estimated to be over CAN $2.7 billion a year, and as much as CAN $4 billion a year when indirect costs are included (Teasell et al., 2008).
With higher life expectancies and an aging population, the incidence of stroke is expected to double in the next decade, and by the year 2025, stroke will be the greatest worldwide cause of disability (Smith & Smith, 2000).

Many people who suffer a stroke face enduring medical challenges, including functional impairments (resulting in difficulty performing even the simplest activities of daily living), cognitive impairments (affecting memory and perception), aphasia and/or other communication difficulties (making it difficult to hold simple conversations), and are at significant risk of subsequent medical complications (such as pneumonia and/or subsequent strokes) (Kind et al., 2007). Due to these complex impairments, stroke survivors have medical needs that span across several sectors of our specialized health care system. As a result, some stroke survivors will require care across multiple care environments. From the initial onset of the symptoms of the stroke, and throughout the recovery process, stroke survivors will transition through emergency, acute, rehabilitation, community, and even long-term care environments. Due to these frequent transfers, stroke patients are at a significant risk of problematic transitions and subsequent medical complications (Cameron, Tsoi, & Marsella, 2008; Kind et al., 2007). Yet, until 2007, no investigation of complicated transitions in stroke patients had been published (Kind et al., 2007). Since their study of 39,384 stroke survivors, Kind et al. (2007) now estimate that at least 20% of all stroke patients will experience at least one complicated transition within the first 30 days post-stroke. These complicated transitions can result in aggravation of existing medical needs, requiring the patient’s return to a higher-intensity care setting (Coleman & Bereson, 2004).
Of all the transitions a stroke survivor will experience, the transition from an inpatient setting to the home environment is the most crucial. The hospital environment is designed to be as patient friendly as possible and a patient’s progress and momentum is often judged against this environment. Upon venturing home, once familiar surroundings suddenly become unfamiliar, and patients suddenly feel their momentum challenged and seemingly reduced (Ellis-Hill, Robison, Wiles, McPherson, Hyndman, & Ashburn, 2009). In describing what it felt like to be discharged home again, a participant in a previous study said, “they prepare you to live in the hospital, and then they discharge you to a place that (feels like) you’ve never been” (Cott, 2004, p. 1416). It is not surprising then, that previous studies have described this particular transition as the most distressing transition a stroke survivor will face (Turner et al., 2007). The lingering impairments that stroke survivors endure can further complicate an already difficult transition for both the stroke survivor and their family caregiver (Cott et al., 2007). Stroke survivors express feelings of anxiety, and are apprehensive that they have not received adequate information about their expected recovery, are ill-prepared for life in the community, and are unable to participate in life in ways they find fulfilling (Cott et al., 2007). In a 2008 review, caregivers of survivors of an acquired brain injury similarly described this particular transition as ‘stressful’, ‘confusing’, ‘busy’, ‘overwhelming’, ‘chaotic’, and ‘frustrating’ (Turner et al., 2008).

The importance of the transition home and back into the community has historically been underestimated, and as a result, severely understudied (Coleman et al., 2005). Thus, despite its importance, very little is known about this transition and what transpires after hospital discharge (Rittman & Van Puymbroeck, 2005). What research is
available surrounding this transition has focused primarily on long term outcomes (greater than 2-years), rather than the initial transition process from the inpatient setting to the home environment (Turner et al., 2008). Furthermore, the majority of this literature is also restricted to retrospective studies (Pringle, Hendry, & McLafferty, 2008), and thus the early discharge experiences of stroke survivors and/or their caregivers is lacking. So, although many researchers see community reintegration as the ultimate outcome of rehabilitation (Winkler, Unsworth, & Sloan, 2006), many discount the fact that successful reintegration of the stroke survivor first begins with a successful transition home.

1.3 Transitioning Home to the Family Caregiver

The transition from hospital to home is a complicated and distressing time not only for the stroke survivor, but also for the family caregiver. Up to 80% of stroke survivors who are discharged from an inpatient facility will return home to the care of a family caregiver (Pringle et al., 2008; Rittman et. al., 2005; Ski & O’Connell, 2007). At this time, responsibility for the patient’s care falls on the family caregiver. During the period leading up to and including the stroke survivors’ discharge, the family caregiver will face immense uncertainties and new challenges. The caregiver must learn to cope with their loved ones’ stroke, their concurrent grief, and an uncertain future. Thus, the sudden need to care for a stroke survivor can be emotionally difficult, and physically challenging (Cameron, Cheung, Streiner, Coyte, & Stewart, 2006). Caregivers are often unsure of their new role, and are unfamiliar with the disease, its progression, and the kinds of supports that are available to them.
In Canada, over 240,000 people provide some form of care for a stroke survivor who is unable to manage alone due to illness, disability, or frailty (Teasell et al., 2008). Studies suggest the number of persons filling a caregiving role will continue to rise in coming years (Waldrop, Kramer, Skretny, Milch, & Finn, 2005). Currently, family caregivers are usually the stroke survivors’ spouse, or adult child (Vincent, Desrosiers, Landreville, & Demers, 2009). The majority of these caregivers are also women, but the proportion of male caregivers has been steadily increasing in recent years (Cranswick & Dosman, 2008). It has been estimated that the unpaid care provided by these family caregivers “spares” the healthcare system billions of dollars annually; the economic value of this unpaid labour has been estimated at around US $257 billion dollars a year (Wilkinson & Lynn, 2005). Thus, caregivers not only play a crucial role in patient care and recovery, but their ability to manage this role effectively is crucial to sustaining our healthcare system (Ski & O’Connell, 2007).

The scope and complexity of the tasks that caregivers attend to is increasing. With approximately 40% of stroke survivors returning home with moderate residual impairments, and an astonishing 15 to 30% returning home with severe residual disability (Lutz, Chumbler, & Roland, 2007), caregivers are not only providing psychological support, they are being asked to fill a medical, coordination, and management role. Caregivers are increasingly expected to manage GI tubes, catheters, and home infusions, in addition to fulfilling caretaking duties, financial obligations, and caring for other family members in the home. The official website of the American Heart and Stroke Association recently listed some of the duties family caregivers’ of stroke survivors attend to. The list suggested family caregivers’ 1) provide physical help with the stroke
survivors’ personal care and transportation, 2) manage financial, legal and business affairs, 3) monitor stroke survivor behavior to ensure safety, 4) manage housework and meal preparation, 5) coordinate health care and monitor medications, 6) help the survivor maintain learned rehab skills and work to improve them, 7) provide emotional support for the stroke survivor and other family members, and 8) encourage the stroke survivor to be as independent as possible (http://www.americanheart.org/, 2007). The list of duties some caregivers take responsibility for is astonishing. One would assume that in order to fulfill all these duties, caregivers should receive adequate preparation from the discharging facility, and/or health care professionals. However, this does not appear to be the case for many caregivers.

As Coleman and Berenson (2004) describe, many family members are abruptly expected to assume a care-giving role in the recovery of their family member’s condition, with infrequent support or preparation. Unlike the caregivers of people with chronic or progressively deteriorating illnesses, there is usually no gradual transition period: Stroke is a sudden event, and caregivers must quickly adapt to their new role. A recent review further suggests that many caregivers report they have not been supplied with the necessary training to enable a successful transition to the home environment (Cameron et al., 2008). Caregivers are rarely trained in supporting activities of daily living, and are rarely given advice on the psychological and emotional impact of stroke, including how to care for a patient dealing with complex emotions (Cameron et al., 2008). In some instances, the transition home is perceived as happening too quickly, before the caregiver can prepare the home, modify their work situations, or sell their home to move in with the person with stroke (Cameron et al., 2008). During a previous focus group for
rehabilitation clients, one stroke survivor described “what is missing from this whole rehab process is any help for the caregivers, cause they’re kind of left out, stressed out and they don’t know which way to turn or whatever. There doesn’t seem to be any help for them …” (Cott, 2004).

Studies have shown that caregivers experience more stress, have lower levels of quality of life, lower subjective well-being, poorer physical health, and less self-efficacy than non-caregivers (Parag et al., 2008; Pinquart & Sorensen, 2007). According to a recent review, between 18% and 35% of caregivers rated their own health as fair or poor (Pinquart & Sorensen, 2007). It is not surprising then that up to 44% of caregivers of stroke survivors will report symptoms of depression within three weeks following the initial transition home (King, Hartke, & Denby, 2007). Caregivers can also experience other types of poor cognitive outcomes in the early phases of caring for a stroke survivor, including severe anxiety, worry, and distress (McCullagh, Brigstocke, Donaldson, & Kalra, 2005). Such anxiety became a strong predictor of future caregiver burden in one study of 300 stroke family caregivers (McCulagh et al., 2005). Sociodemographic characteristics are also associated with caregiver outcomes. For example, younger caregivers, caregivers who rate their own health as poor, and those who perceive their workload as high are also at an increased risk of facing caregiver burden (Hasemann, Kesselring, Stocklin, & Grabel, 2007). When compared to their male counterparts, female caregivers often experience distress and burden earlier on in the caregiving trajectory (Simon, Kumar, & Kendrick, 2009).

Beyond health related concerns, caregiving may also negatively impact relationship dynamics, for example, one study found family caregivers often felt so
overwhelmed during the transition home that the strain led to a relationship breakdown, and/or other family disputes (Turner et al., 2007). It is worth noting, however, that the act of caregiving may not be an entirely negative experience for all. In a study of 85 stroke family caregivers, over 90% of survey respondents said that caring for a stroke survivor increased their appreciation of life (Haley, Allen, Grant, Clay, Perkins, & Roth, 2009). Caregivers in this study also described enjoying the feeling of being needed and appreciated (Haley et al., 2009).

Maintaining a high sense of caregiver well-being is an important concern, not only for caregivers themselves, but stroke survivors as well. Recent studies have revealed that a stressed or ill-adapted caregiver can negatively affect the rehabilitation process for the patient with stroke, and consequently, the need for long-term hospitalization of the patient will increase (Franzén-Dahlin et al., 2006). With the current nursing home costs in Canada for stroke survivors estimated at over CAN $600 million dollars a year (Teasell et al., 2008), it is not clear whether the current system could support a greater number of stroke survivors living outside the home. Thus, in order to make it possible for patients to live at home after a stroke without risking the physical and/or psychological health of the caregiver, it is essential to provide preparation, and give extra support to caregivers in transition (Cameron & Gignac, 2008; Franzen-Dahlin et al., 2006).

1.4 Overview of Stroke Rehabilitation in Ontario

Although significant improvements have been made to reduce the incidence of stroke (through public awareness campaigns and primary prevention), and lower its
impact (with innovative techniques such as thrombolytic therapy), these improvements are not expected to reduce the burden of stroke in the face of shifting demographics (Teasell et al., 2008). Thus, the greatest opportunity for a successful life after stroke may lie within a well-organized rehabilitation system that supports its stroke survivors and their family caregivers.

Ontario is Canada’s largest province, with a better-developed stroke rehabilitation system compared to other provinces and territories (Teasell, Meyer, Foley, Salter, & Willems, 2009). Despite this, however, stroke rehabilitation care in Ontario is variable at best. Individuals experiencing a stroke in Ontario will receive emergency and acute care within the publicly funded health care system. Here, many will be seen by a neurologist, and receive some form of rehabilitation therapy. However, therapist-to-patient ratios are also variable (for example, therapist-to-patient ratios for speech-language pathology range from 1:15 to 1:54) (Teasell, et al., 2009).

Following treatment in an acute-care setting, some individuals will receive in-patient rehabilitation at a rehabilitation-specific centre. Between 1995 and 1998, the Ontario Stroke Rehabilitation Consensus Panel reported on the admissions rate for stroke in the Province. On average, only 14% of stroke patients went to rehabilitation hospitals, while 65% were sent directly home (with or without care), 12% were sent to chronic care hospitals, 9% to nursing homes, and 5% to acute care hospitals (Teasell, et al., 2009). For those who do receive in-patient rehabilitation, many will experience a trend towards shorter hospital stays, and a reduction in available beds, and a loss or reduction in out-patient therapies.
In June 2000, the Ontario government invested $70 million for a 40-year implementation phase, followed by $30 million per year in new funding to support the creation and continuation of the Ontario Stroke System (OSS) (Teasell, et al., 2009). The OSS has aimed to decrease the incidence of stroke, and increase the quality of patient care and outcomes for persons with stroke (Lewis, Trypuc, Lindsay, O’Callaghan, & Dishaw, 2006). Research data have demonstrated that despite the aging and growth of our population, the rates of hospitalization for stroke have decreased (Lewis, et al., 2006). Thus suggesting the OSS is meeting its goals of improving stroke care in Ontario, and setting precedence for other initiatives in the province.

The Canadian Stroke Network was formed in 1999 with the goal of reducing the impact of stroke on Canadians, ensuring the best knowledge is applied and building Canadians’ capacity in stroke research (www.canadianstrokenetwork.ca, 2009). In 2003, the Canadian Stroke Network held a consensus panel to discuss the areas of stroke rehabilitation that required additional research and urgent attention. Based on this review, the panel compiled a list of five priority areas in stroke rehabilitation. At the top of this list (of highest priority) was a need for further research and investigation into programs that would enable stroke survivors and their family caregivers to reintegrate into the community successfully following a stroke (Bayley et al., 2007). Since this time, little research has emphasized stroke survivors’ transitions back into the community. Of particular concern, is the resulting lack of evidence that is available to support existing programs. Evidence-based practice implies that the care is up-to-date, based on the best evidence, and is “proven effective” (Teasell, Folley, Bhogal, Bagg, & Jutai, 2006). Without an empirically valid knowledge base, rehabilitation care providers have no way
of knowing if an alternate plan would yield superior results and/or lower costs (Teasell et al., 2006). An example of a program that has great potential to support the transition process, yet lacks empirical knowledge, is the weekend pass portion of inpatient rehabilitation.

### 1.41 Weekend Home Passes

When a stroke removes a patient from their family and environment, and changes them greatly by illness, an “uncomfortable incongruence” between the person and their environment may be expected upon their return home (Davidson & Young, 1985, p. 127). Familiar territory may become unfamiliar, while family roles and responsibilities shift. Weekend home passes offered during inpatient rehabilitation may provide an opportunity to prepare patients and their family caregivers for this eventual transition home (See Figure 1). These home passes have the potential to afford stroke survivors and their family caregivers the chance to practice living in the home environment prior to being fully discharged. Through the weekend pass, problems that might develop after discharge may be recognized earlier on and resolved (Bertram, Tesman, & Michela, 1970).

### 1.42 Weekend Pass Process and Potential Benefits

At rehabilitation centers in Ontario, patients who participate in weekend passes will have a family caregiver pick them up from the facility on a Friday evening, and transport them back to their home. The family caregiver and the patient will then spend
the weekend (including overnights) together in the home environment, going about
everyday activities as best they can. Throughout the weekend, the family may encounter
difficulties such as trouble with a thick carpet, issues with a raised doorstep, or difficulty
understanding the survivors’ need to use the bathroom. On Sunday evening, the caregiver
will bring the patient back to the rehabilitation facility, where the patient will continue
with in-patient therapy for the rest of the week. Patients and caregivers have the potential
to utilize several weekend passes before their final discharge home. In this way, weekend
home passes, in theory, may help ease the transition home by providing a valuable
glimpse into what life will be like post-discharge. This is an extremely important
opportunity, for as Olofsson et al. (2005) suggests, it is only once the patient and
caregiver are home that they can truly understand the full consequences of the illness and
resulting disability.
**Figure 1:** Demonstration of the placement of weekend passes in the stroke care trajectory. Weekend passes occur during the transition from the rehabilitation facility to the home environment.

Weekend home passes also have the potential to provide valuable insight into the preparedness of the patient and caregiver for discharge home. These visits to the home can further lead to recommendations regarding the person’s ultimate likelihood of returning to the home environment safely, or regarding the need for additional support in the home. If utilized properly, such an experience prior to hospital discharge would allow rehabilitation facilities the opportunity to suggest necessary home modifications, or give extra support to families in need. Studies have shown that such support and preparation
for caregivers can reduce the rates of re-hospitalization (Coleman, Parry, Chalmers, & Min, 2006), and improve stroke caregiver quality of life (Shyu et al., 2007). Further studies suggest that such “hands on” training in the day-to-day management of stroke patients was associated with lower anxiety and burden in caregivers (McCullagh et al., 2005). Once again, a caregiver with lower levels of distress can more easily maintain the caregiving role, and thus the need for long-term hospitalization of the patient may decrease (Frazen-Dahlin et al., 2007). Further evidence also supports that initial gains in rehabilitation are more effectively maintained if the family is healthy and involved (Greenwood, Mackenzie, Cloud, & Wilson, 2008).

1.4.3 The Existing Problem

The increasing emphasis placed on discharge has resulted in the implementation of services like weekend passes. Unfortunately, according to Pringle et. al. (2008), this emphasis has not been matched by research supporting such services, or investigations into the impact such services have on caregivers (Pringle et al., 2008). Consequently, although weekend home passes are commonly employed, there exists a severe lack of literature surrounding their use.

A thorough literature search (from earliest to 2009) using variations of the key words “weekend pass”, “weekend visit”, “home pass”, and “home visit” revealed there were no references directly examining the process of weekend passes; no references were found investigating the effectiveness of weekend passes within the stroke population; and lastly, no references were found discussing patient or caregiver experiences and
perceptions of weekend passes. The only available literature of any relevance to weekend passes was found in 1) seven articles discussing weekend passes as a method to introduce occupational therapy visits in the homes of geriatric clients, and 2) two studies discussing weekend passes as a mode of measuring patient versus caregiver appraisals of symptoms and illnesses (see Table 1). Even then, the majority of these studies were underpowered, and suffered other methodological concerns.

Because no research or literature exists investigating the use of weekend passes, there is no way of knowing if the current arrangement is meeting the needs of patients and their caregivers. A lack of evidence-base further questions whether weekend passes adhere to a rigorous standard of care, and if they are associated with better overall care, and outcomes. Furthermore, since there has been no investigation of the perceptions of those involved, we do not fully understand the experiences of its users. Thus, it is not clear what it feels like to care for a stroke survivor throughout a weekend pass. Such an understanding would allow for improved and more focused preparation for going on a pass, and follow-up services could then operate with greater awareness (Pringle et al., 2008, p. 2395), and more focused supports.

Thus, an important preliminary step in investigating weekend passes would be to gain feedback on the experiences of its users (such as the family caregivers and/or stroke survivors). As supported by Ellis-Hill and colleagues (2009), if services were created to help and support family caregivers, then research must gain an understanding of their perspectives (Ellis-Hill et al., 2009). Without it, this opportunity to support and prepare families for discharge may not be utilized to its fullest extent. Furthermore, to date, the majority of existing transition interventions have been directed at the stroke survivor
rather than the family caregiver. This has become a common complaint of caregivers’;
typically interventions and care plans are developed that will require their involvement to
implement, but family caregivers are often not consulted, or considered in the plan’s
feasibility (Coleman & Berenson, 2004). By initially investigating weekend passes from
the perspectives of the family caregiver, we will have the opportunity to understand their
experiences and corresponding needs, which ultimately affect the stability of the
transition, and the stroke survivor’s recovery.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Title</th>
<th>Research Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rao, N., Sullivan, L.,</td>
<td>1986</td>
<td>Rehabilitation Team and Family Assessment of the Initial Home Pass</td>
<td>To compare functional ratings obtained from family and rehabilitation team members during a home pass.</td>
</tr>
<tr>
<td>Young, CL, &amp; Harvey, RF.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Henderson, E. &amp; Pentland, B.</td>
<td>1991</td>
<td>Home Pass Assessment in Neuro-rehabilitation Practice</td>
<td>To find the difference between families and healthcare professionals' perceptions of patient status at the time of home pass.</td>
</tr>
<tr>
<td>Patterson, C., &amp; Mulky, G.</td>
<td>1999</td>
<td>The Effectiveness of Predischarge Home Assessment Visits: A Systematic Review</td>
<td>To conduct a systematic review to evaluate the effectiveness of pre-discharge home assessment visits for elderly patients.</td>
</tr>
<tr>
<td>Pardessus, V., Puisieux, F., Di</td>
<td>2002</td>
<td>Benefits of Home Visits for Falls and Autonomy in the Elderly: A Randomized Trial Study</td>
<td>To investigate whether home visits by an occupational therapist reduces the risk of falling and improves the autonomy of older patients hospitalized for falling.</td>
</tr>
<tr>
<td>Pompeo, C., &amp; Gaudefroy, C.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mountain, G., &amp; Pghills, A.</td>
<td>2003</td>
<td>Pre-discharged Home Visits with Older People: Time to Review Practice.</td>
<td>To investigate the practice of pre-discharge home visits with frail older people.</td>
</tr>
<tr>
<td>Ramsdel, J., Jackson, J., Guy, H., Renvall, M.</td>
<td>2004</td>
<td>Comparison of Clinic-based Home Assessment to a Home Visit in Demented Elderly Patients.</td>
<td>To investigate the yield of a targeted, structured, comprehensive clinic-based home assessment performed by a nurse specialist, by comparing the results of clinic-based and in-home assessments of fraildemented patients.</td>
</tr>
<tr>
<td>Turrell, S., Davis, R., Graham, H., and Weiss, I.</td>
<td>2005</td>
<td>Adolescents with Anorexia Nervosa: Multiple Perspectives of Discharge Readiness</td>
<td>To investigate the conditions that must be in place to help adolescent patients and their families gain the confidence needed to continue recovery at home, following the adolescents' hospitalisation for anorexia nervosa.</td>
</tr>
<tr>
<td>Lammin, N., Clemmon, L.,</td>
<td>2007</td>
<td>Feasibility and Results of a Randomized Pilot-Study of Pre-Discharge Occupational Therapy Home Visits.</td>
<td>To investigate the feasibility of a randomized control study to measure the effect of a pre-discharge home visit with an Occupational Therapist on functional performance.</td>
</tr>
<tr>
<td>McCluskey, A., Lin, C., Cameron, I., &amp; Barras, S.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
RESEARCH OBJECTIVES

The current study will examine the weekend pass from the perspective of the family caregiver. In this way, we will have an opportunity to understand their experiences and perspectives in the process. This investigation will serve as one portion of a larger study which will also collect stroke survivors’ and health care professionals’ opinions.

Accordingly, the objectives of the current study will be to: 1) examine family caregivers’ perceptions of, and experiences with, weekend home passes during inpatient rehabilitation, and 2) receive feedback on the educational and support needs of family caregivers to inform the delivery of future weekend home passes.
CHAPTER 2

METHODOLOGY

“the real has to be described, not constructed or formed”

(Merleau-Ponty, 1962, as cited in Upton, & Reed, 2006, p.1241).

2.1 Introduction

Understanding the experiences of family caregivers while caring for a stroke survivor over a weekend pass requires a strategy that not only acknowledges the details and complexities of caring for a loved one, but also recognizes the subjectivity and humanness of caregivers’ experiences. As Upton and Reed (2006) suggest, a past preoccupation with typically narrow research approaches has delayed the essential development of an accurate understanding of the lived caregiving experience. The ability of a healthcare team to provide accurate support to family members is often based on their understanding of the family members’ experiences (Penner & McClement, 2008). A gap in our understanding of caregiving experiences is therefore highly problematic, and warrants a study with a methodology specifically aimed at understanding such lived experiences. Because of this, the present study has chosen to use a Husserlian phenomenological approach to investigate the topic presented. A rigorous phenomenological approach will yield findings that can provide a valid understanding of caregivers’ experiences. The knowledge generated by such a phenomenological study will offer a foundation for future psychological/educational intervention studies involving
caregivers. Moreover, it will enhance the evidence-based knowledge available to clinicians in order to effectively support families (Penner & McClement, 2008).

The current chapter will present: 1) a brief background on the philosophical and methodological underpinnings of phenomenology, 2) a description of the phenomenological interpretation chosen for the present study, and 3) a description of the research design employed in the present study.

2.2 Exploring the Method of Inquiry

Qualitative research aims to describe and interpret social rules, cultures, and human experiences. Qualitative research is well suited to exploratory investigations of problems about which little is known (Sinuff, Cook, & Giacomini, 2007). At the risk of oversimplifying, qualitative research has several theories and methodologies, each with a different aim and a different assumption (Finlay, 2000). The list is long: ethnography, phenomenology, grounded theory, hermeneutics, conversational analysis, and feminist theory, to name a few. When faced with a number of methodological options within the qualitative paradigm, the method of choice is that which provides the researcher with the most complete picture of the developing phenomenon, and thus elicits the greatest gain in understanding (Conklin, 2007).

Because the main objective of the present study is to understand and describe the experiences of family caregivers caring for a stroke survivor over a weekend pass, a phenomenological methodology was chosen. Phenomenology appears most appropriate for the present study as I am not attempting to generate a theory (as in grounded theory methodology), or interpret a cultural or social group (as in an ethnography), or the
experiences of one individual (as in a case study, or biography). Instead, I am aiming to gain rich descriptions of caregivers’ experiences, in their own words, without external interpretations. Phenomenology holds these goals in high regard. Phenomenology, above all other methods, “honours human experiences” (Smith, 1999). It is because of this core value, that phenomenology has become one of the dominant qualitative perspectives employed by health researchers today (Dowling, 2005). Phenomenology attempts to describe the experience of a phenomenon, whether that is an event, or an object (Finaly, 2000). Its aim is to illustrate the world of the participant to help researchers interpret and understand the experiences under investigation (Smith, 1999). This deeper understanding is facilitated through descriptions and reflections, as well as directing our awareness of the phenomena in an attempt to reveal its inherent meaning (Munhall, 1994).

Phenomenology is not just a research method; it is also a philosophy and an approach (Omery, 1983). This dual identity, coupled with the many different and sometimes conflicting perspectives within phenomenology, causes confusion for some. Thus, the subsequent section will describe phenomenology, first in its philosophical roots, and secondly in its use as a research method. Once a better understanding of phenomenology has been reached, I will discuss the specific phenomenological interpretation chosen for the current study (Section 2.3).

### 2.2.1 The Philosophical Phenomenological Movement

Phenomenology as a philosophy has a long history. Throughout what is referred to as the “phenomenological movement,” many unique philosophers developed their own
interpretation of the principles of phenomenology. It is often said that there are as many styles of phenomenology as there are phenomenologists (Spiegelberg, 1982). It would be impossible to describe each interpretation in-depth here, so instead, major philosophers will be discussed as they appear throughout the phenomenological movement.

The history of phenomenology can be divided into three main phases. The first phase is referred to as the *preparatory phase*, in which phenomenology was first introduced as a method of inquiry (Munhall, 1994). Franz Brentano (1838-1917) was the forerunner of the phenomenological movement during the preparatory phase, and throughout the last half of the nineteenth century (Munhall, 1994). Central to Brentano’s philosophy was the concept of *intentionality*. Intentionality reminds us that every mental act is related to some object (Dowling, 2005). It is the idea that when we view an object or an event, we perceive it, and it is those perceptions that have meaning. Furthermore, intentionality refers to the internal experience of being consciously aware of (and thus perceiving) something (Dowling, 2005). Intentionality has developed into one of the fundamental assumptions of phenomenology today (Munhall, 1994).

The second phase in the phenomenological movement is referred to as the *German phase* (Munhall, 1994). The prominent scholars dominating phenomenology in the early twentieth century were the German philosophers Edmund Husserl, and Martin Heidegger. Husserl was a prominent student of Franz Brentano. Husserl acknowledges *experience* as the fundamental source of knowledge. For Husserl, the aim of phenomenology is the rigorous and unbiased study of things as they appear, in order to elicit an essential understanding of human consciousness and experience (Dowling, 2005). Husserl believed that subjective information should be important to scientists
seeking to understand human perceptions and actions. Because human beings go about their day-to-day lives with little critical reflection on their experiences (often engaging in a taken-for-granted attitude), Husserl believed that a scientific approach was needed to elicit the essence of lived experience (Lopez & Willis, 2004). The essence can be described as the experience before human nature interprets it, or applies our ways of understanding to it. Husserl also believed that there are features to any lived experience that are common to all persons who share that experience. These are referred to as universal essences. Again, it is these essences that are considered to represent the true nature of the phenomenon being studied (Lopez & Willis, 2004).

In an attempt to expose these universal essences, Husserl developed what is known as the phenomenological reduction. The concept of the phenomenological reduction (also known as bracketing) is key in the discussion of Husserl’s phenomenology. Husserlian reduction “demands for the researcher to approach the study without any preconceived notions, conceptual frameworks, or expectations, and to bracket-out or suspend any pre-understandings and/or assumptions” (Munhall, 1994, p. 299). In this way, reduction allows the researcher to see an object “again for the first time,” viewing it without any preconceived ideas or interpretations. According to Husserl, in order for one to understand the structure of something, one has to practice reflection, and a certain level of reduction (Munhall, 1994). An often cited example is the notion of the phenomenological chair: try viewing a chair and removing all your preconceived ideas about it; remove thinking about what you interpret its structure as; and remove what you interpret about its function. In this way, you will soon be able to see the chair again for the first time. You can now focus solely on the phenomenon at
hand, rather than your interpretations of it. Reduction as a method can be used in degrees: layers can be peeled back one at a time, slowly exposing the phenomenon you wish to study (Munhall, 1994).

Not all philosophers at this time agreed with Husserl that such a reduction was possible. One such prominent philosopher (the second philosopher of the German phase) was Martin Heidegger. Heidegger was a student of Husserl’s who challenged some of his teacher’s assumptions of phenomenology (Lopez & Willis, 2004). Heidegger combined Husserl’s philosophies with existentialism, the idea that individuals create their own meanings in life. He claimed that ‘one is what one does in the world.’ Heidegger’s ideas are primarily concerned with ‘meaning finding.’ Heidegger has proposed going beyond the mere description of essences (as discussed by Husserl) to find meaning embedded in life practices and experiences (Lopez & Willis, 2004). The focus of Heidegger’s ideas is on what humans experience rather than what they consciously know. The Heideggarian phenomenologist will focus on describing the meaning of the individuals “being-in-the-world” and how these meanings influence the choices they make (Lopez & Willis, 2004 p. 729). One of Heidegger’s main contributions was his influence on the third phase in the phenomenological movement: the French phase.

The most prominent philosophers of the French phase include Gabriel Marcel, Jean-Paul Sartre, and Maurice Merleau-Ponty (Munhall, 1994). Of these philosophers, Merleau-Ponty’s work has become quite popular in health-related phenomenological research. According to Merleau-Ponty, we as humans are always conscious of something: as he suggests, this is not an inner existence, but simply life itself (Munhall, 1994). Merleau-Ponty’s phenomenology is not interested in the abstract, but rather in the current
experiences of a ‘historical person,’ as they live in and engage with the world. In this way, Merleau-Ponty also seeks to understand people as beings in a given situation (Munhall, 1994, p. 301).

The process of phenomenological inquiry attempts to provide a framework of understanding for the lived experiences of human beings. Throughout the course of history, this philosophy has taken on many forms, first exploring individual essences and experiences with the ultimate aim of deriving meaning, to trying to establish the meaning of living itself. Given this broad spectrum of philosophical depth behind this concept, it is up to each new researcher to decide which stance he or she will use to address each individual research question. The choice of inquiry will shape not only the outcomes of various qualitative perspectives, but also illustrate the core ideologies each researcher holds in approaching a particular problem.

2.22 Phenomenology as a Methodological Approach

As a philosophy, phenomenology is associated with the writings of Husserl, Heidegger, and Merleau-Ponty (Dowling, 2007). However, these important phenomenological philosophers did not offer a method of utilizing phenomenology in healthcare research. Researchers such as Giorgi, van Manen, Colazzi, and van Kaam have built upon this philosophy and are now associated with phenomenology as a research method. Many of these phenomenological ‘methodologists’ utilized the teachings of the philosophers, and created informed research methods. In order to perform what Giorgi (2000) refers to as “scientific practices,” the teachings and insights of the
phenomenological philosophers needed to be mediated. As Dowling (2007) further explains, if researchers today simply practiced phenomenology as Husserl suggested it, they would be practicing philosophy, not research.

Although there are a number of interpretations, there are approximately four main methodologies created for phenomenological research (Munhall, 1994). These include the methods as proposed by Giorgi (1970), van Kaam (1959, 1969), Colazzi (1978), and van Manen (1984). All four methodologists utilize a very similar sequence of steps (see figure 2.1 for a detailed chart as proposed by Munhall, 1994, adapted from Omery, 1983). However, each method is regarded as more suitable for different types of phenomenological studies. For example, Colazzi’s method, as it is based on the principles of Heidegger, is more suited towards studies utilizing Heideggarian phenomenology (Dowling, 2007). Giorgi’s work, on the other hand, possesses a human science approach to phenomenology, and follows the rigorous work of Husserl (Dowling, 2007).

<table>
<thead>
<tr>
<th>Comparative Approaches- Major Steps in Each Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Munhall, 1994, adapted from Omery, 1983)</td>
</tr>
</tbody>
</table>

Van Kaam (1969)

1. Preliminary considerations
2. Identification of the research questions evoked by the experience
3. Awareness phase of explication
4. Scientific explication
5. Final identification and description of data

Giorgi (1970)

1. Description of experience gained through qualitative interviews
2. Interviews to be transcribed
3. Transcripts are read several times in entirety
4. Transcripts are read once more slowly to begin to elicit meaning units
5. Text is divided into meaning units, redundancies are eliminated, and the participants’ language may be transformed to the language of the researcher.

6. Meaning units are organized into clusters

7. Clusters are linked in an understandable pattern, similar to themes

8. Transcripts are re-read to ensure results reflect original data

Colazzi (1978)

1. All subjects’ oral and written descriptions are read in order to obtain a feel for the whole

2. Significant statements and phrases pertaining directly to the phenomenon are extracted

3. Meanings are formulated from these significant statements and phrases

4. Meanings are clustered into themes

5. Results are integrated into an exhaustive description of the phenomenon

6. Researcher returns to participants with descriptions for validation.

Van Manen (1984)

1. Turning to the nature of the lived experience, committing to the world

2. Existential investigation

3. Phenomenological reduction

4. Description of the phenomenon through the art of writing and rewording

<table>
<thead>
<tr>
<th>Figure 2. Description of comparative phenomenological methodology approaches</th>
</tr>
</thead>
</table>

Although there is not one phenomenological methodology, the varieties of the methods all hold the primacy of the subjective experience as the central aim (Creswell, 1998). Previous phenomenological research studies have employed a variety of these methods. Which method to use is again based on the researcher’s judgment, and the question seeking to be answered.
2.3 Application of the Method of Inquiry to the Study of Family Caregivers’ Experiences with the Weekend Passes

Now that an overview of the different philosophical and methodological interpretations of phenomenology has been presented, the following section will describe the specific phenomenological orientation I chose to investigate the current study.

2.3.1 My Philosophical Orientation

Although there are several philosophical interpretations of phenomenology, one interpretation appeared particularly useful to the study of family caregivers’ experiences during weekend passes. Specifically, phenomenology as proposed by Husserl, appeared to be especially useful for the present study.

For Husserl, the aim of phenomenology is to arrive at an essential understanding of human experiences (Dowling, 2007). In the same way, the present study aimed to gain an understanding of the experiences of caregivers during weekend passes. Lopez and Willis (2004) suggest that a Husserlian approach is particularly useful when examining features of experiences that may have a direct application to healthcare practice. This is because a central assumption in Husserlian phenomenology is that there are common features to any lived experience that all people who have the experience share (Lopez & Willis, 2004). For example, in the phenomenological study by Sargent and Wainwright (2007), survivors of an emergency liver transplant described a change in their outlook on life which was felt by all interviewed patients. Thus the authors considered a change in
outlook characteristic of being an emergency liver transplant recipient (Sargent & Wainwright, 2007). In a similar way, the information gathered regarding the experiences of caregivers’ during weekend passes could be transferable to future caregivers in their situation, thus informing future practice. Furthermore, a Husserlian approach to answering research questions appeared more appropriately suited to the present study. As Lopez and Willis (2004) explain, a Husserlian phenomenologist will answer research questions quite differently than a Heideggarian phenomenologist. For example, a Husserlian phenomenologist would ask a working mother to “describe what is like to be a working mother,” and follow up with questions to arrive at common concepts integral to the experience. A Heideggarian perspective, however, would obtain the participants’ description of a typical day, and then encourage the participant to describe experiences of time, workload, relations, and experiences of the body, to place the lived experience in the context of daily work (Lopez & Willis, 2004). The open-ended but direct questions and outcome of central themes, as proposed by Husserl, appeared to be a more suitable fit for my research question and style of inquiry. In this way, we could gain an understanding of the common concepts vital to the experience of caring for a stroke survivor over a weekend visit.

### 2.32 My Methodological Approach

For the present study, I chose to use the phenomenological method proposed by Amedeo Giorgi (2000). Of all the ‘methodologists,’ Giorgi is one of the few who continues to write about phenomenology as a method for the human sciences (Dowling,
Giorgi’s work has also had a profound impact on health care research. Numerous phenomenological research projects in the health sciences have utilized his methods (e.g. Sargent & Wainwright, 2007 and Upton & Reed, 2006). In addition, Giorgi’s human science approach closely follows the principles proposed by Husserl. The methods proposed by Van Kaam (1969), Colazzi (1978), and Van Manen (1984) were not chosen for the present study as they are directed towards studies utilizing a Heideggarian perspective, and/or are not as well-validated as the methods proposed by Giorgi (2000).

According to Giorgi (1970), there are three main criteria that are essential to any phenomenological study utilizing a Husserlian perspective. The first criterion is to obtain detailed descriptions of the lived experience in question from others. This can be gained through in-depth interviews, for example. The second criterion is the phenomenological reduction. As described previously, this tool is used to allow the researcher to be fully present to the descriptions of the phenomenon as presented by the participants. Thirdly, there must be a search for scientific essences. Found within the data, these essences are again the basic and fundamental commonalities of the phenomenon (Corrigan et al., 2007). The present study has incorporated each of these three criteria proposed by Giorgi throughout the research protocol.

### 2.4 The Research Protocol

The following section will now describe how the chosen philosophical framework, and method of inquiry were utilized in the present study.
2.41 Research Design

In phenomenological research, data are collected through open-ended and in-depth qualitative interviews (Penner & McClement, 2008). To accomplish Giorgi’s first criterion of obtaining comprehensive descriptions of the phenomenon from others, the family caregivers of stroke survivors involved in weekend passes from in-patient rehabilitation were asked to participate in two in-depth interviews. The first interview took place within one week following the first scheduled home visit, while the second interview took place two weeks after the stroke survivor had been fully discharged home. I suspected that having two interviews at different time periods would allow us to extract different kinds of information. For example, I proposed that the first interview would elicit initial reactions to weekend passes, while the second interview would allow participants to reflect back on their overall experience and have a more complete understanding of the process. As Seidman (2006) suggests, utilizing more than one phenomenological interview with a particular participant is beneficial, as it provides a foundation of detail that helps illuminate the next. In the same way, I felt that having a series of interviews would increase the participant’s comfort level with the researcher, and thus elicit more honest and open responses as the interviews progressed.

2.42 Data Collection

The in-depth interviews followed a semi-structured interview guide to focus discussion on caregivers’ experiences with weekend home passes (see appendix).
Caregivers were asked to reflect back on their feelings, and preparation received prior to the first weekend pass. Additionally, caregivers were asked to describe any benefits they perceived as offered by home passes, and the areas they felt were in need of improvement. The interview guide was designed to allow caregivers to discuss their experiences openly, without being “led” by the investigator. To accomplish this, the interview guide was created using a Husserlian perspective, with a minimal number of broad questions, and a series of open-ended probes, which are used to clarify the meaning of responses and encourage in-depth discussions. Such a guide allowed participants to discuss what they deemed as important, while still remaining focused on the goals of the study. Family caregivers who tended to focus on the stroke patients’ needs, were encouraged to think about their own needs by the interviewer.

Interviews were one-on-one (one caregiver and one researcher), and took place in person (in a private room at the rehabilitation facility), or over the telephone at the caregiver’s convenience. The rationale for using the two methods to gather data is based on the qualitative study of 43 correctional officers and visitors to county jails in the Northwestern United States. This study, by Sturges and Hanrahan (2004), sought to expand the knowledge of qualitative researchers on the differences in rigor in telephone interviewing versus in-person interviewing. Through their investigation, the authors demonstrated that there were no differences in the quantity or quality of data elicited during an in-person interview versus an interview via the telephone. Further, in our own experience, an added advantage to telephone interviewing is that a greater variety and larger number of caregivers may be able to participate. This may be due to the fact that some caregivers find it difficult to arrange transportation and a time to meet with an
investigator when interviews are only offered in person. Also, some caregivers do not like individuals (often strangers) coming to their home as they feel the added pressure of keeping their home clean and see it as an intrusion on their privacy.

Throughout the interviews, the researcher also attempted to maintain a level of reduction, refraining from outside interpretations by bracketing preconceived notions. As Upton and Reed (2006) suggest, phenomenological reduction does not involve an absence of presumptions, but a consciousness of one’s own assumptions. This open awareness was practiced not only throughout the interview process, but into the data analysis phase as well. Interviews were digitally audio recorded and transcribed verbatim by a professional transcriber.

2.43 The investigator's own Assumptions and Biases

By describing biases and preconceived notions upfront, the researcher can push back, or consciously bracket assumptions in an effort to look at the phenomenon as if for the first time, and genuinely from the perspective of the participant.

Biases that may influence my perception of this study come from my previous involvement in caregiver studies. As part of a research team assessing and investigating the needs of caregivers of stroke survivors, I became aware that typically few resources were made available to caregivers. Caregivers are then often poorly prepared for their role in the care of a family member who has suffered a stroke. One specific study stands out in my mind as a source of potential bias. In a previous study performed by our research team, caregivers explicitly described weekend passes as difficult and that they
“wouldn’t wish them upon anyone else.” Of course, this opinion has provided positive motivation to initiate this study. However, I must continue to bracket my preconceived notions that the feelings were specific to the weekend passes and not to the general experience of having their family member back home for the first time. I have attempted to remain open minded, and true to the descriptions each caregiver has presented.

2.44 Research Participants

The current study aimed to recruit approximately 15 family caregivers providing care to a stroke survivor throughout a weekend pass. Phenomenological studies involving Giorgi’s method typically have a smaller sample size (previous studies involving approximately 6 to 11 participants e.g. Sargent & Wainwright, 2007). However, as I anticipated a level of dropout in the study after the first interview, I chose to recruit up to 15 caregivers for the first interview, with the aim of retaining at least ten participants for the follow-up interview. Thus, the sample size will be consistent with previous studies. I defined family caregivers as the person primarily responsible for providing and/or coordinating stroke survivor care throughout the weekend pass, without financial compensation to do so. In this way, the family caregiver may be a relative or friend. If there appeared to be more than one family caregiver, I invited the family member who co-resided with the stroke survivor and who, in discussion with the family, was likely to be primarily responsible for care in the home.

Recognizing the variability in family caregivers’ experiences, I recruited using a maximum variation sampling strategy. In this way, I aimed to gain information and
perspectives from a broad range of caregivers, including: male and female caregivers, spouses, parents, and adult children. Such a strategy challenges the investigators’ own preconceived understanding of the phenomenon being studied as a variation in responses is likely to be obtained (Crabtree & Miller, 1999). Sampling in this manner therefore reinforced the study’s phenomenological foundation. For example, by including both male and female caregivers I had an opportunity to understand both genders’ experiences as they contributed to the broader essences of the caregiving experience. Participants were included if they were able to read, speak, and comprehend English. All participants provided informed consent, and voluntarily agreed to participate in the study.

Study recruitment took place at a rehabilitation facility in a large urban area in Ontario. Access into the hospital was gained through members of the stroke team who are also investigators on this project. To accomplish study recruitment, the graduate student attended weekly stroke rounds. Here the clinical team identified families who would be partaking in weekend passes for each upcoming weekend. I then had the opportunity to approach family members within the week following their first scheduled weekend home pass. I explained the study, answered any questions the family caregivers had, and asked if they would voluntarily like to participate in the study. At this time, the family caregiver signed the informed consent form. Ethical approval was gained from the rehabilitation hospital’s ethics board, as well as the research ethics board at the University of Toronto.
2.45 Data Analysis

The professionally transcribed qualitative interviews were first reviewed for accuracy. Afterwards, Giorgi’s (1970) principles of data analysis were used. As suggested by Giorgi, transcripts were read in their entirety several times, in an attempt to gain an understanding of the text as a whole. Once understood, transcripts were read once more, slowly, to identify components or differences not by frequency, but by intuitive judgment made by the researcher. Next, the text was divided up into meaning units. Meaning units were then clustered in larger categories. This process also eliminated redundancies, and clarified the meanings of each unit in relation to each other. NVivo 2 qualitative software was then used to organize the transcripts into the meaning units and categories. From this level of analysis the clusters of meaning units were organized into emerging themes. As a last step, the original text was re-read to ensure that the themes reflected the original data, and that no meanings were overlooked. Once again, the researchers’ own previous experience with caregivers and in-patient rehabilitation were acknowledged, reflected upon, and bracketed in order to remain open and sensitive to the phenomenon throughout the analysis process.

2.46 Acknowledging Limitations and Increasing Rigor

Using qualitative methods, there are opportunities for confusion, misunderstanding, and uncertainty. As such, phenomenological researchers need to
anticipate and accept such limitations because phenomenology really *is* a big, and often overwhelming, philosophical aim (Munhall, 1994).

First and foremost, phenomenology asks us to liberate ourselves from any presumptions we may carry with us into the field. The notion that this is even possible is a limitation of phenomenology to some (Lowes & Prowes, 2000). Skeptics suggest that such an act would render researchers mute (Conklin, 2007). However, phenomenologists today suggest that reduction does not have to be absolute. Rather, reduction should involve the consciousness of one’s presumptions, and an awakening from a blase attitude into a feeling of curiosity (Conklin, 2007; Upton & Reed, 2006). Interpreted this way, phenomenological reduction is a useful research tool, rather than a source of confusion or a threat to the study’s rigor.

Munhall (1994) suggests that one of the leading sources of improved rigor, or merit, in a phenomenological study comes from the “phenomenological nod” (also referred to as the phenomenological Ah-ha by some). This occurs when people hearing or reading our work nod in agreement. Having others read our work and ‘nod’ can also confirm the study’s resonance (whether the interpretation of the phenomenon resonates with people), representativeness (if the results accurately represent the lived experiences), and responsiveness (how individuals respond to the results) (Munhall, 1994). All three of these criteria are useful in increasing the merit of the study. Thus, a phenomenological nod was incorporated into my data analysis steps, and came from the supervising committee on the project. This phenomenological nod also served as a means of peer debriefing, or secondary opinion, and thus also provided a way of testing the researchers’ interpretations against those of an outside reviewer’s. In this way, I have further ensured
the representativeness of my research findings, and thus increased the overall merit of the study’s results (McReynolds, Koch, & Rumrill, 2001).

Next, as suggested by Lincoln and Guba (1985) for any qualitative research, certain steps must be taken to ensure the trustworthiness of the data. These two authors suggest there are four criteria for establishing such trustworthiness, including credibility, dependability, confirmability, and transferability. The first criterion here, credibility, refers to ones “confidence in the truth of the data and the interpretations of them” (Polit & Beck, 2004, p. 430). Such credibility can be improved by a prolonged engagement with the data at both the data collection stage as well as the data analysis stage. The use of in-depth interviews in the present study has allowed for such a thorough review of the phenomenon, as these types of interviews encouraged the emergence of open and detailed discussions. Giorgi’s suggestions for data analysis encouraged the careful reading of entire transcripts to ensure that meaning units and interpretations came from the data, rather than having the data be borne out of a researcher’s own preconceived notions. In this way, I became confident that my results represented the data truthfully. The second criterion, dependability, refers to “the stability of data over time and over conditions”, similar to the idea of reliability (Polit & Beck, 2004, p. 434). In the present study, I have ensured dependability by collecting data at two separate time points from each caregiver in the study. In this way, I was able to collect descriptions of the weekend pass over time to ensure caregivers’ opinions of them were reflected accurately and consistently. The third criterion, confirmability, refers to the “objectivity or neutrality of the data” (Polit & Beck, 2004, p. 435). In the present study, such neutrality was maintained through the use of bracketing, at both the data collection stage, as well as the data analysis phase.
Bracketing is a key source of such neutrality in phenomenological studies (Polit & Beck, 2004). The final criterion, transferability, refers to the extent to which the findings can be transferred to others (essentially the generalizability of the data) (Polit & Beck, 2004). This particular criterion is said to be a sampling and/or design issue. In the present study, we ensured the transferability of our data by conducting recruitment through the use of a maximum variation sampling strategy. In this way, our respondents represented a variety of groups, including women and men, sons, daughters, daughter-in-laws, and significant others. Recruitment was also sensitive to a variety of ethnic and cultural backgrounds, encouraging everyone who participated in the weekend pass process to discuss their experiences with me. Once again, the use of all four of these criteria have ensured the trustworthiness of my results.

Lastly, as a final consideration, the nature of qualitative outcomes must be emphasized. Future results from the current study are in no way meant to predict or generalize, instead they will serve to enlighten health care professionals of the experiences that family caregivers may have while partaking in the weekend pass element of in-patient rehabilitation.

2.5 Summary

As described in-depth previously, the present study employed the following methodological steps:

1. Biases and previous assumptions were bracketed
2. Two semi-structured qualitative interviews were performed with the caregivers of stroke survivors

3. Interviews were transcribed professionally and checked for accuracy by the investigator

4. Transcripts were read several times in entirety

5. Once understood, transcripts were read once more, slowly

6. Text was divided into meaning units

7. Meaning units were organized into clusters

8. Clusters were then linked in an understandable pattern to reflect the “essences” (similar to the development of themes)

9. Transcripts were re-read to ensure the findings reflected the original data

10. The “phenomenological nod” (or peer debriefing) was gained to test the researcher’s interpretation against that of an outside reviewer.
CHAPTER 3

MANUSCRIPT

A phenomenological study of the experiences of family caregivers partaking in a stroke survivor’s weekend pass

A. MARSELLA¹, J. FRIEDLAND¹,², D. RICHARDSON³, & J.I. CAMERON¹,²,³

¹Graduate Department of Rehabilitation Science, University of Toronto, ²Department of Occupational Science & Occupational Therapy, ³University of Toronto, Toronto Rehabilitation Institute
Abstract

*Purpose:* To understand the experiences of family caregivers who care for a stroke survivor throughout their weekend passes from an in-patient rehabilitation facility.

*Method:* Utilizing a Husserlian phenomenological perspective, we interviewed 15 family caregivers of stroke survivors on two separate occasions: within one week after their family members’ first weekend pass, and again two weeks after their final discharge home. Interviews followed a semi-structured interview guide, and were audio recorded. Interviews were transcribed verbatim, and analyzed using the principles outline by Giorgi (1997).

*Results:* Caregivers described their perceptions of, and experiences with, weekend home passes. Analysis of the caregivers’ descriptions of their experience resulted in five themes: (i) Caregivers feel overwhelmed throughout the weekend pass process, (ii) Access to supportive resources influence caregiving experiences, (iii) Caregivers adjust to the weekend pass throughout its subsequent use, (iv) Caregivers feel a responsibility and a need to be included by health professionals in the care of their family stroke survivor, and v) Caregivers describe the weekend pass as a means towards recovery.

*Conclusions:* By educating and supporting caregivers throughout the weekend pass, by ensuring tangible supports are in place, and by including caregivers in care planning, health care professionals can increase the positive experience of caregivers, and optimize the opportunity to prepare caregivers for the eventual transition home.

*Keywords:* Stroke, caregiving, transition, discharge, weekend pass, rehabilitation, qualitative
Introduction

Stroke is the fourth leading cause of death and a leading cause of long-term disability in Canada (Health Canada, 2000). Survivors of stroke face enduring medical challenges, including functional impairments, aphasia or other communication difficulties, and are at significant risk of subsequent medical complications (Kind et al., 2007). Due to these complex impairments, stroke survivors have medical needs spanning several sectors of our specialized health care system. From the initial onset of the symptoms of the stroke, and throughout the recovery process, stroke survivors will transition through emergency, acute, rehabilitation, community, and even long-term care environments. Of all the transitions a stroke survivor will experience, the transition from an inpatient setting to the home environment has been described as the most distressing transition a stroke survivor will face (Turner et al., 2007). With up to 80% of stroke survivors returning home after in-patient care (Pringle et al., 2008; Rittman et. al., 2005; Ski & O’Connell, 2007) this transitional period is also a difficult time for family caregivers. In the absence of stroke specific data, caregivers of survivors of acquired brain injury describe the transition home as ‘stressful’, ‘confusing’, ‘busy’, ‘overwhelming’, ‘chaotic’, and ‘frustrating’ (Turner et al., 2007).

Family caregivers play an essential role in supporting stroke survivors who return home with varying levels of physical, emotional, and cognitive difficulties (Cameron & Gignac, 2008). With such patients being discharged sooner from in-patient settings (Clarke & Rosen, 2001) caregivers are increasingly expected to manage medical needs, and provide psychological support to the patient, in addition to fulfilling caretaking
duties, financial obligations, and caring for other family members in the home. Unfortunately, caregivers rarely receive adequate preparation or support for this role and, as a result, often experience stress and negative health consequences (Cameron et al., 2006; Pinquart & Sorensen, 2003) that can compromise patient rehabilitation outcomes, or threaten the sustainability of home care (Franzén-Dahlin et al., 2006).

With the current nursing home costs for stroke survivors estimated at over CAN $600 million dollars a year (Teasell et al., 2008), it is not clear whether the current system could support a greater number of stroke survivors living outside the home. Thus, in order to make it possible for patients to live at home after a stroke without risking the physical and, or, psychological health of the caregiver, it is essential to provide preparation, and give extra support to both the patients and the caregivers in transition (Cameron & Gignac, 2008; Franzen-Dahlin et al., 2006).

Weekend home passes offered during inpatient rehabilitation were designed to support the stroke survivor’s transition home, and begin to prepare the family caregiver for their new caregiving role. Such visits to the home afford stroke survivors and their family caregivers the chance to practice living in the home environment prior to being fully discharged from inpatient care. In this way, problems that might develop after discharge can be recognized earlier on and resolved (Tesman & Michela, 1970). Although weekend home passes are commonly used, we were not able to locate any formal investigation into the process. Thus, there is no way of knowing whether this current arrangement is actually meeting the needs of its users, or fulfilling its objectives.
In turn, health care professionals and researchers question whether these passes are indeed associated with improved transitions, or better overall care and outcomes. Of paramount concern, is that the opinions of those involved have never been investigated. Consequently, we know little of the experiences of family caregivers as they care for a stroke survivor throughout a weekend pass. As Ellis-Hill and colleagues (2009) have suggested, if we want to provide services that are more supportive of families following stroke, it is necessary to gain an understanding of their perspectives. Until we learn more of the experiences of caregivers, we remain uncertain if weekend passes actually support them in their role, and help facilitate the difficult transition home. Gaining such an understanding would allow for improved and more focused preparation for the weekend pass, and follow-up services could then also operate with greater awareness (Pringle et al., 2008).

**Purpose**

The purpose of the current study was to gain an understanding of the experiences of family caregivers caring for stroke survivors throughout a weekend pass. In this way we will: 1) examine family caregivers’ perceptions of, and experiences with, weekend home passes during in-patient rehabilitation, and 2) examine family caregivers’ experiences with being prepared for the weekend pass to inform the delivery of future weekend home passes.
Methods

Orientation:

Understanding the experiences of family caregivers while caring for a stroke survivor over a weekend pass requires a strategy that not only acknowledges the details and complexities of caring for a loved one, but also recognizes the subjectivity and humanness of caregivers’ experiences. Because of this, the present study has used a Husserlian phenomenological approach. Husserlian phenomenology focuses on descriptions about situations from the individuals who experience them, in the manner in which they are experienced (Giorgi, 2000). As Parahoo (1997) further suggests, a phenomenological approach is useful in a study of experiences about which little is known, as it ensures the research remains focused on the participants perspectives.

Study Design:

The caregivers of stroke survivors involved in weekend passes from in-patient rehabilitation were invited to participate in two in-depth interviews. The first interview took place within one week following the first scheduled home pass, while the second interview took place two to four weeks after the stroke survivor had been fully discharged home. We suspected that having two interviews at different time periods would allow us to extract different kinds of information. For example, we proposed that the first interview would elicit initial reactions to weekend passes, while the second interview would allow participants to reflect back on their overall experience and have a more complete understanding of the process, and ultimate transition home.
Table 1- Sample interview questions from the semi-structured interview guide

1. Your family member has had a stroke, can you please share with me [stroke survivor’s name]’s “stroke story,” describing the journey from the initial symptoms of the stroke, up to this point?

2. The stroke survivor recently came home for the weekend on a weekend pass. Can you please describe your experiences with the weekend pass in your own words?
   Probes:  - What were you feeling before you took your loved one home?
   - What information, training, and or support did you receive in regards to the weekend pass?
   - Did anyone help you or provide any assistance to you in caring for the stroke survivor over the weekend?
   - How was the timing of weekend pass for you?

The in-depth interviews followed a semi-structured interview guide to focus discussion on caregivers’ experiences with weekend home passes (See Table 1).
Caregivers were asked to describe their “stroke story”, as well as reflect back on their feelings, and preparation received prior to the first weekend pass. Additionally, caregivers were asked to describe the benefits they perceived as offered by home passes, and any areas in which they thought could use improvement. Interviews were one-on-one (one caregiver and one researcher), and took place in person (in a private room at a rehabilitation facility), or over the telephone at the caregiver’s convenience. Previous studies have demonstrated that upon comparison, there are no significant differences in the results elicited during an in-person interview versus an interview via the telephone (Sturges & Hanrahan, 2004). Thus, both methods were utilized to appeal to a wider range of caregivers. To maintain the phenomenological orientation of the study, throughout
each interview the researcher undertook a process of ‘bracketing’ out her previous understanding of caregivers’ experiences. The term bracketing describes the act of suspending preconceived notions, and personal interpretations. Bracketing is one component of the phenomenological reduction. All interviews were audio-recorded and professionally transcribed.

Participants:

The current study aimed to recruit approximately 15 family caregivers providing care to a stroke survivor throughout a weekend pass. Phenomenological studies typically have a smaller sample size (previous studies involving approximately 6 to 11 participants e.g. Sargent & Wainwright, 2007). However, as we anticipated a level of dropout in our study after the first interview, we chose to recruit up to 15 caregivers for the first interview, with the aim of retaining at least ten participants for the follow-up interview. Family caregivers were defined as the person primarily responsible for providing and/or coordinating stroke survivor care in the community without financial compensation. If there appeared to be more than one family caregiver we invited the family member who co-resided with the stroke survivor and who, in discussion with the family, was likely to be primarily responsible for care in the home to participate. Participants were selected using a maximum variation sampling strategy in order to elicit a broad range of experiences (e.g., from sons and daughters, spouses, grandchildren and friends of varying ages). Study recruitment took place at a rehabilitation facility in a large urban centre in Ontario. Ethical approval for the study was obtained from the Institutional Research Ethics Board (2008), and The University of Toronto Research Ethics Board (2008).
Data Analysis:

Data analysis commenced after the last interview was completed, and followed the principles indicated by Giorgi (1997). To begin, transcripts were read several times in their entirety, in an attempt to gain an understanding of the text as a whole. Once understood, transcripts were read once more, slowly, to identify components or differences not by frequency, but by intuitive judgment made by the researcher. The researchers intuitive views of the data were recorded in a journal. Next, the original text was divided up into meaning units. Meaning units were then clustered in larger categories representing similar meanings. This process also eliminated redundancies, and clarified the meanings of each unit in relation to each other. NVivo 2 qualitative software was used to organize the transcripts into the meaning units and categories. From this level of analysis, the clusters of meaning units were structured into categories, and eventually into emerging themes. As a last step, the original text was re-read to ensure that the themes reflected the original data, and that no meanings were overlooked. Once again, the researchers’ own previous experience with caregivers and in-patient rehabilitation were acknowledged, reflected upon, and bracketed in order to remain open and sensitive to the phenomenon throughout the analysis process.

Results

Participants

A total of 15 family caregivers (13 female) were recruited for participation in the current study. An additional eight caregivers met the inclusion criteria for the present
study, but were not interested in participating and/or did not return our telephone calls. As per the sampling criteria, all caregivers recruited were caring for a stroke survivor throughout the weekend pass element of in-patient rehabilitation. The average age of participating caregivers was 40.8 years. The caregivers’ relationship to the stroke survivors varied between daughters (n=7), sons (n=2), granddaughters (n=1), daughter-in-laws (n=1), close friends (n=1), and spouses/significant others (n=3). Overall, the number of weekend passes offered to each family (who completed the second interview) also varied, with some families only participating in one pass, while other families participated in up to six weekend passes (median = 3 passes). Lastly, the length of time between admission to the rehabilitation hospital and the first weekend pass varied between one day to forty-three days (median = 17 days).

Interview times lasted anywhere between nine minutes and forty-six minutes (median = 11 minutes). Overall, all caregivers were extremely happy to participate in this study and share their experiences with the weekend pass. One caregiver noted “I was actually really glad when I got the message from you (the researcher), because I did want to share this, but I didn’t know who to share it with” (CG10, Interview 1). Only four caregivers could not be reached for their second interview (three were lost to follow-up, and one relocated out of the country).

**Findings**

Five themes, each containing sub-themes, emerged from the interview data. Each theme provides insight into the experiences of caregivers while caring for a stroke survivor throughout a weekend pass. The five themes are: 1) Caregivers feel
overwhelmed throughout the weekend pass, 2) Access to supportive resources influences caregivers’ experiences over the weekend pass, 3) Caregivers describe adjusting to the weekend pass through its subsequent use, 4) Caregivers feel a responsibility and a need to be included by health professionals in the care of their family stroke survivor, and 5) Caregivers describe the weekend pass as a means towards recovery. Each of these themes encapsulates the unique individual and communal experiences of caregivers partaking in weekend passes for the first time. The order of presentation here is not indicative of their importance to the experience. The following is a presentation of each of the five themes, including a description of each overall theme, followed by the presentation of each of the sub-themes.

**Theme 1- Caregivers feel overwhelmed throughout the weekend pass process.**

Caring for a stroke survivor throughout a weekend pass meant feeling overwhelmed for all caregivers in our study. Caregivers were taking on new responsibilities at this time, and began to feel the demands the weekend pass placed on them. Such demands included assisting the stroke survivor in their daily activities (such as assisting them to the washroom, or in the shower or bath), as well as providing emotional and psychological support. A feeling of being overwhelmed also came from the additional demands a weekend pass placed on caregivers, including having to understand and dispense new and often serious medications, and having to exit the security of the hospital and bear full responsibility for the survivor throughout the weekend. These new duties meant caregivers needed to shift responsibilities, and in turn they experienced a greater burden, and a lack of time for themselves and for their
previous obligations. Overall, even though caregivers described the trying nature of the weekend pass, they also described it as a struggle worth enduring for the sake of their loved one’s well-being.

**Providing Assistance in Daily Activities**

A feeling of being overwhelmed emanated when caregivers described the tasks they bore responsibility for throughout the weekend pass. Caregivers were often left to organize and provide care for the survivor, manage their medications, and maintain the home. One of the most overriding duties caregivers performed was assisting the stroke survivor throughout basic everyday activities in the home. In supporting a patient in everyday activities, caregivers were left with little time for themselves or for doing their own regular tasks. One caregiver described her experience helping the stroke survivor from one room to another in their house on their first weekend pass:

> Its very hard for me, because every time he goes upstairs, I’m going up and down and up again … with the walker and so on … it’s hard eh, you have to put aside all of the time at this stage … You can’t get involved in anything else, cause you’re going to be called [to help]. (CG11, Interview1).

**Providing Emotional Support**

Aside from the constant physical attention given to survivors, many caregivers were not ready for the psychological/emotional support that they would be called upon to provide. Most caregivers in the study described feeling drained emotionally themselves,
and thus, having to comfort another while feeling this way proved to be difficult for many. Caregivers were unprepared to provide such emotional support, which in turn proved to be an overwhelming experience. One caregiver, who was a significant other, described her struggle with providing such support:

I wouldn’t say difficult maybe sometimes a little frustrating … because I’m trying … I’m trying to keep his spirits up… and I have to keep explaining that everything is good, and you know the worst is over, um, I’m trying to get him to focus on just getting better, going through his therapy ... and getting better. It’s a little bit hard... (CG04, Interview1).

Bearing Sole Responsibility

In addition to all the duties performed throughout the weekend, most caregivers in our study described their need to supervise and help the stroke survivor at all times. Such a sense appeared to originate from the feeling that caregivers were now the sole practitioner of the survivor’s care, and that they now bore full responsibility of the patient. The health and safety of the patient was now entirely “on their watch,” whereas they had previously had the security of the hospital. Thus, even when the stroke survivor was able to manage to some degree on their own, caregivers still insisted on maintaining vigilance in their role. Two caregivers spoke candidly about this experience as follows:

Well um … in terms of like walking around and stuff, I think it’s fine but definitely he needs to have somebody there … like I don’t leave him by himself
... I didn’t leave him alone (on the weekend pass) ... (CG8, Interview1).

Um … with showering… he’s able to do on his own … uh mind you I’ve been in close proximity, I’m not doing … anything else (CG12, Interview1).

It is important to note also, that in one case, after caring for a stroke survivor throughout a weekend pass, one adult daughter caregiver in our study realized she could no longer deal with the time constraints and physical demands the weekend pass placed on her. In turn she decided to not participate in any further passes. Her experience is described as follows:

She’s (the stroke survivor) not coming this weekend … she realizes she’s can’t come this weekend … its just not possible … I really need a weekend to myself … I also need to get stuff done for me as opposed to… cause I’m in school, and trying to do all of this … this is a little overwhelming (CG15-Interview1).

A Struggle Worth Enduring

Overall, despite the load of the weekend pass, all caregivers (with exception of one, as discussed above) in our study described a willingness to continue participating in the weekend pass process. Caregivers appeared willing to put the stroke survivors’ needs above their own in a self-sacrificial way. Caregivers were very determined to do
whatever it took to help the stroke survivor in their recovery, despite feeling overwhelmed. In particular, two caregivers said:

It is, um, eh, it is … I’m not going to say a chore, but it (the weekend pass) is a task … and um… you know, but … you know if that helps [the stroke survivor] … if that’s what makes him feel better, than that’s what we’ll do (CG12, Interview 1).

It was a lot of work … but… I’ll do anything, that’s fine … (CG8, Interview 1).

Theme 2- Access to supportive resources influence caregiving experiences throughout the weekend pass.

Sufficient supportive resources appeared to increase the positive experiences of caregivers throughout their weekend passes. Supportive resources here refer to both tangible resources, such as home modifications and assistive aids, as well as social support resources, such as help from a family member, friend, or health care professional. Such support appeared to enable caregivers in their new role, and provided them with the confidence they needed to facilitate a positive weekend experience.

Access to Tangible Resources

Access to tangible resources, such as home modifications, and assistive devices positively benefited both caregivers and stroke survivors throughout the weekend pass. Such resources supported caregivers in their daily activities, and thus alleviated some of
the caregiver’s burden. In many cases, such tangible supports actually gave the stroke survivor back an element of independence; an endowment which caregivers felt grateful for. Two daughter caregivers described such support as follows:

Once we got the shower seat it was a pure miracle when it came on Christmas day, because then, it took away all the excess stress … cause then [the stroke survivor] could have her own bath, and she can do everything herself (CG05, Interview2).

[The stroke survivor] is doing a lot better … he’s moving around a lot … he has a rollator now and he goes everywhere with that … like he’ll go down to like the grocery store and put stuff in his basket and come back… he’s going all over the place! (CG07, Interview2).

On the other hand, many caregivers in our study also described the difficulty they encountered while trying to assist throughout a weekend pass without such tangible supports. Those caregivers who reported not receiving the tangible supports such as home modifications, or assistive devices reported mediocre experiences, and an increase in frustrations throughout the weekend pass. A lack of tangible resources simply made things more difficult for the family caregiver. For example, two daughter caregivers described their experiences as follows:
[The weekend pass] is kind of like a first time and it’s exciting but it’s also frustrating. But it’s even more frustrating when you … at the rehab like you have uh, all accessories, right like a washroom, accessible, and like everything … then when you go home, it’s like nothing … right, and like you don’t even know how you can go to the washroom … (CG01, Interview2).

You have to do sponge baths, also do the exercises and do the meals, and all the blood pressures, blood sugars, and then keep track of the doctors and everybody else you have to meet … and then … you have to also walk the person to the bathroom … when usually they can do those things themselves, but because the bars and stuff are not there … you have to (CG05, Interview2).

In turn, many caregivers suggested such tangible supports (such as home modifications and assistive devices) should be set up before the weekend passes commenced. Caregivers felt that having such supports in place would have made their caregiving duties less burdensome, less frustrating, and the overall weekend pass experience would have been “safer.” Two caregivers described their views on this as follows:

All the things … to prepare a house for um … like if the stroke patient has some disability … it needs to be done ahead … like way earlier, because it’s usually too late like … a person goes home and nothing’s done, I think it needs to be done a bit earlier. Like that patient, when [they] come home for the first time, at least
something will be done to make it easier to be home, right? Like it’s, it’s frustrating anyway, right? (CG01, Interview2).

I don’t know if they wait until the person goes home permanently but quite, quite frankly if the person’s gone home even for the weekend the [home modifications] should probably be done then (CG09, Interview1).

**Support from Health Professionals**

Supportive resources, such as psychological support or training, provided by health care professionals further enabled caregivers in their role. Caregivers felt more confident in their abilities to provide care after receiving such preparation and support. All caregivers in our study described welcoming this support from the health care team. One daughter caregiver described how support and training from the rehabilitation staff members helped her family through their weekend pass:

[The rehab team] showed us how to do all the cleaning and meds and like the feeds and all that stuff … the nurses showed me and then they showed my mom as well, so we both knew how to use it all … and they taught my Dad as well … I think everything went really well (over the weekend) (CG07-Interview1).

**Support from Family and Friends**

Similarly, caregivers who received help from family and friends felt reassured, and were able to perform caregiving duties more confidently. Often times, without such
help, caregivers felt they would not have been able to perform such duties. One daughter caregiver described the help she received from her family throughout the weekend pass:

My brother-in-law was here, he met us here (at their house), so between the two of us we managed to get [the stroke survivor] up the ramp, in the chair … my sister came in the morning and went home at night when I got home from work … which was like 24 hour care [chuckles]. I don’t know how people do it if they don’t have anybody … to help (CG13-Interview2).

Like the above caregiver, others reported receiving such support from neighbours and friends. Once again, this help and support made caregivers feel more comfortable and confident in assisting the stroke survivor. One wife caregiver described getting support from a neighbour while transferring the stroke survivor from the car into the house on their first weekend pass:

The neighbour, you know he’s a handyman, he does stuff for me, so I said, be here and help us out … it was icy… and I knew if [the stroke survivor] fell out there (in the driveway) I’d have a hell of a time. So I, I’ve got resources here, in the sense of … there are people around, who’ve been wonderfully helpful (CG11, Interview1).

Notably, caregivers who reported receiving sufficient support appeared more optimistic and cheerful about their experiences throughout the weekend pass. In contrast,
caregivers who reported a lack of supportive resources expressed more frustration, and negative views of the weekend pass process. Contradictory to the above quotations, one daughter caregiver who did not receive support from her family described her experiences as follows:

I’m the oldest … so I’m expected to drop everything, [it’s] a little overwhelming … I get no time … I feel like I’m working ten days a week. They (both the health care team and the family) want me to be there all the time, and I just can’t do that. I need time to, eh, a weekend uh, you know I’m running out of supplies, I’m not taking care of what I need to for my own home … (CG15, Interview1).

Theme 3- Caregivers describe adjusting to the weekend pass process through its subsequent use.

Caregivers in our study described a positive adjustment to the weekend pass throughout its subsequent use. During the first series of interviews (after the first weekend pass) the majority of caregivers reported feeling anxious or nervous in anticipation of the pass. Such anxiety was likely attributable to the angst of the approaching responsibility, and perhaps a doubt in their own abilities. However, for caregivers who were able to participate in more than one pass, this nervousness appeared to dissipate as the passes progressed. Caregivers became more self-confident and comfortable in their role. Caregivers described a “learning by doing,” and found self-assurance through practice.
Anticipatory Anxiety

Caregivers often described themselves before the first weekend pass as “anxious,” and “nervous.” Caregivers often did not divulge what it was exactly that they were nervous about, but many caregivers implied that they simply wanted everything to go okay for the stroke survivor, and that they wanted the stroke survivor to be safe and happy in their care. Two daughter caregivers spoke candidly about their own anticipatory anxiety as follows:

I was kind of anxious (to bring the stroke survivor home)…hmm… I shouldn’t say kind of- I was very anxious (CG13, Interview1).

I was nervous at first because I’m clucky, and ah like to worry about things ... [the stroke survivor] has had this stroke, and she’s been away for a long time, and … I wanted everything to be proper and yap, yap, yap .. that’s me (CG14, Interview1).

Subsequent Visit Experience

The nervousness referred to in the first home visit was described as melting away after a series of weekend passes. Such anxiety may have been dispelled by a “learning by doing” action described by most caregivers. During the second series of interviews, all caregivers reported feeling better adjusted to their weekend pass experience. For example, one daughter caregiver spoke of their succeeding experiences as follows:
I mean … you feel more, more comfortable and you … are not as afraid as the first time, cause you feel that you can do this … (CG5, Interview2).

The decrease in nervousness also appeared to reflect the progress made by the stroke survivor in the intervening time:

Every time we had [the stroke survivor] back like it was a lot easier … and he was also improving too so, that was making it even easier for us … so it was a lot of both … we learned a lot as it progressed and he progressed as it went (CG7, Interview 2).

**Theme 4- Caregivers feel a responsibility and a need to be included by health professionals in the care of their family member.**

Caregivers in our study described feeling a need to be included in the stroke survivors’ care by the health care team. Caregivers expressed this need as wanting to be ‘kept in the loop’ and informed of the stroke survivors’ current rehabilitation status. Caregivers needed to be accepted and included, and provided with any and all information that could be attained. Caregivers seemed to understand that soon full medical care and support for the stroke survivor would be placed on them, and thus, they needed to be involved as much as possible by the current health practitioners. Caregivers described this as a need to be informed, a comfort in being involved, and saw a future of family centered care.
**Needing to be Involved**

Caregivers described wanting health professionals to be forthcoming with information pertaining to their loved one’s care. Caregivers were able to acknowledge the ‘business’ of staff members’ schedules, however they still felt time needed to be set aside to inform families, specifically caregivers’, who were preparing to care for a stroke survivor over a weekend pass. Caregivers wanted to be spoken to, and have their own voices heard by health professionals. One daughter caregiver described her views on involving families in the stroke survivor’s care:

I, I think it’s good for the family to be involved and to know what’s going on. I realize that when you are dealing with the public some of them don’t know what you’re talking about and some of them don’t care. But I think that the majority of us want to know what’s going on … and if we don’t understand it immediately then we need to have it explained to us in some terms that we do. We all need to be involved in our own health care, and we need to be involved in whatever needs to happen for people for whom we’re taking at least some responsibility for (CG14, Interview2).

**Comfort from Being Involved**

Some caregivers described such involvement from the team as comforting, and felt more prepared for their role as a primary caregiver when such involvement was established. This comfort helped them not only in providing care, but there was also an
emotional benefit achieved. Two caregivers described this comfort in the following ways:

[The health care team] keeps you … like they… make sure the caregiver knows what’s going on … and it gives them more like … feel more comfortable and they have an idea of what’s going on. So then you can, cause a person with stroke … well if they have any kind of injury, they can’t remember things or whatever … they might lose track of memory sometimes. So that way the caregiver can keep track of what’s going on (CG5, Interview2).

I probably hung out most over there (at the rehabilitation hospital), but my entire family was … very well informed, very encouraged to be there and like support [the stroke survivor] … we were filled in on a lot of things, we tagged along a lot (chuckles) … but definitely (thinks more families should be involved), cause it kind of, it’s support for the individual as well as the family gets to be involved in the process .. so it’s .. it’s good emotionally (CG7, Interview2).

**Family Centered Care**

Many caregivers in our study advocated for the future of such family involvement. Many saw this involvement as representing a family-centered approach, rather than a strictly patient-centered approach by care professionals. Caregivers realized it would be them who would bear the task of caring for the patient once they left hospital,
and thus stated that more families should be involved in their stroke survivor’s care. One caregiver spoke candidly about this when she said:

I think uh, what needs to be done more is actually … working with families … Talking to families, showing them what needs to be done. And like … talking to them … basically because, um it’s everything … mostly on their relatives’ shoulders right, like a person goes home after rehab … if they are living with family or spouses or whatever it is … right. So I think it needs to be more work with uh, spouses like what relatives or whatever it is (CG1, Interview2).

**Theme 5- Caregivers describe the weekend pass as a means towards recovery**

Caregivers in our study described the weekend pass as a necessary, and generally beneficial, means towards the stroke survivor’s final discharge. Caregivers perceived a number of benefits coming from their participation in the weekend pass process. Caregivers saw not only themselves as benefiting from them, but also the stroke survivor and other family members as well. They described the weekend pass as an opportunity to rehearse their caregiving role. Caregivers also described the weekend pass as a physical therapy opportunity for the patient, and described the emotional benefits it provided both the family and the survivor.

**Caregiving Role Rehearsal**

Caregivers in our study described the opportunity to practice having the stroke survivor home a major benefit intrinsic in weekend passes. A successful weekend pass
gave caregivers confidence in knowing they could handle having the stroke survivor home with them. Such an opportunity was also welcomed before final discharge as it gave the caregivers piece of mind knowing that certain obstacles could still be “fixed” before the final discharge home. This was described in the following ways:

I finally got to find out what I was going to deal with on a full time basis (CG04, Interview1).

I was happy to get [the stroke survivor] home and see how she was doing, knowing that if I was concerned, I could give her back and, and … get some tune ups, before she was home so to speak (CG14, Interview2)

**Physical Therapy**

Caregivers in our study also described a physical benefit achieved by the stroke survivor over the weekend pass. Caregivers perceived the daily activities performed throughout the weekend (such as walking up steps and on-top of carpeting) as aiding the stroke survivors’ physical recovery. Caregivers also thought this physical interaction with their home environment gave the survivor an idea of what they should work on in therapy in the hospital. For example, a patient who had difficulty with the stairs in their home would be able to ask their therapist to demonstrate useful strategies come Monday. Caregivers spoke of this benefit in a very positive light, and sounded encouraged by the fact that being home had progressed the survivors’ recovery. In this way, caregivers
described the weekend pass as a mode of therapy for the survivor. Two caregivers described this as follows:

(After the weekend pass) [her son] thought [the stroke survivor] was moving her … lifting her foot better. The right foot, and then she said we’ll I guess it’s probably because of the rug! I guess where she is down there (at the Rehab hospital) there’s no rug … you have a tendency to slide a little more, where here, she has to make her foot lift, you know (CG3, Interview1).

[The stroke survivor] was excited to go back to rehab, cause he kind of like knew what he did over the weekend, and could kind of take with that … and go to rehab and work on things that he now knows to work on, and things that maybe he didn’t realize he could do without it. You kind of realize what things you need to work on (CG7, Interview1).

**Emotional Gains**

Aside from the physical benefits, caregivers saw the weekend pass as benefiting the stroke survivor emotionally. In turn, these emotional benefits could be passed on to the caregivers themselves, as well as their other family members. Caregivers were grateful for the sense of normalcy it gave them being outside the hospital. The weekend pass also allowed families to be together once again, in their own homes. Two caregivers described this as follows:
I think it does [the stroke survivor] a lot of good personally, and um, just being home with his family is a good thing, it was good for me, good for his daughter, we all enjoyed it … (CG8, Interview1).

Its good, its just like, very, it just felt like Christmas … you can just relax, you don’t have to get up early in the morning to go to rehab and do exercises, you could just, it’s more easier that way, you just keep your pajamas on and do things in a more calm state (CG5, Interview1).
The Phenomenon of the Weekend Pass Caregiving Experience

Caregivers feel overwhelmed throughout the weekend pass process, through:
- Providing assistance in daily activities
- Providing emotional support
- Bearing sole responsibility
- A struggle worth enduring

Access to supportive resources influences caregiving experiences throughout the weekend pass, through:
- Access to tangible resources
- Support from health professionals
- Support from family & friends

Caregivers describe adjusting to the weekend pass process through its subsequent use, between:
- Anticipatory anxiety
- Subsequent visit experience

Caregivers feel a responsibility and a need to be included by health professionals in the care of their family stroke survivor, through:
- A need to be involved
- A comfort from being involved
- Family centered care

Caregivers describe the weekend pass as a means towards recovery, as it is:
- A role rehearsal opportunity
- A mode of physical therapy
- An emotional gains opportunity
Discussion

This phenomenological research study has focused on the experiences of 15 stroke family caregivers who have utilized weekend passes as a method of facilitating the transition from an in-patient rehabilitation facility to the home environment. Previous literature has demonstrated that this particular transition is especially difficult for family caregivers, yet their perspectives in the use of weekend passes were unknown. In response, our study has addressed this gap in the literature by gathering and understanding family caregivers’ experiences with the weekend pass. Five themes captured family caregivers’ experiences with the weekend pass including caregivers’ feelings of being overwhelmed by the pass; the caregiving experience changed through the weekend pass’ subsequent use; caregiving was influenced by the presence of supportive resources (such as tangible supports, as well as social support mechanisms); the weekend pass was seen as an overall means towards recovery by caregivers; and lastly, caregivers expressed the need to be acknowledged and involved by health professionals in the care of their loved one.

Gaining Support

For the patient, homecoming is a time of regaining control of one’s life, and a re-engagement in enjoyable activities (Olofsson et al., 2005). However, the opposite may be said for the family caregiver. Caregivers in our study described the plethora of tasks they bore responsibility for throughout the weekend pass, including caring for the patient both physically and psychologically, as well as managing household tasks and previous
obligations. In turn, many caregivers described the weekend pass experience as an overwhelming time.

Previous studies have demonstrated that an overwhelmed stroke caregiver will result in increased utilization of healthcare resources, and a premature institutionalization of the patient (Franzén-Dahlin et al., 2007). Thus, it is in the interest of health care professionals utilizing weekend passes to facilitate the transition home to minimize caregivers’ experiences of being overwhelmed. Increasing supportive resources may prove to be a useful way of moderating the overwhelming nature of the weekend pass. In our study, access to supportive resources (such as social support from family members, friends, and health professionals, as well as access to tangible supports, such as home modifications and assistive devices) was perceived as increasing the positive experiences of caregivers throughout the weekend pass. This observation is supported by previous research studies that have described the buffering effect social support may have in preventing the negative health outcomes, which would otherwise have been predicted (Friedland & McColl, 1987). Specifically, supportive resources may contribute to positive caregiver adjustment, as well as higher levels of well-being and general health in stroke family caregivers (Grant, Elliot, Weaver, Glandon, Raper, & Giger, 2006). In spite of these findings, however, previous studies have shown that one in four stroke caregivers feels dissatisfied with the support level offered by rehabilitation centers, while nearly one in five stroke caregivers indicate not receiving any support at all from rehabilitation teams (Visser-Meily, Post, Schepers, Ketelaar, van Heugten, & Lindeman, 2005). This is an astonishing figure considering our findings on the moderating effects
such support has. By providing support resources, rehabilitation facilities can further increase the positive experiences of caregivers and stroke survivors.

In our study, several caregivers reported receiving support from health care professionals, but even these caregivers continued to feel overwhelmed. One possible explanation is that health care teams are not providing the right preparation to caregivers who are embarking on weekend passes. Previous studies have shown that a primary complaint of caregivers’ is that supports do not offer enough practical advice, and should focus more on caregivers’ specific problems (Visser-Meily et al., 2005). Further, as Cameron and Gignac (2008) have demonstrated, stroke caregivers’ support needs dramatically increase when they are preparing to return home with the stroke survivor (during “the preparation phase”). As suggested, stroke caregivers preparing to take on the role of primary caregiver require information about community services (such as respite, and stroke programs), emotional support from health care professionals (to lessen anxiety and fears at this time), and feedback from rehabilitation professionals (to increase caregiver confidence and skill) (Cameron & Gignac, 2008). Thus, in order to maximize the benefits achieved by caregivers, healthcare professionals should consider tailoring supports specifically to the needs of caregivers’ engaging in weekend passes, including implementing more practical ‘hands on’ preparation and more personalized social supports. With more appropriate supportive resources in place, families may feel less overwhelmed, better supported, and achieve greater role preparation.
Adjusting to the Process

Stroke caregivers in our study described the weekend pass as an overall beneficial experience, which not only granted them normalcy in being home together as a family again, but also gave the caregiver a chance to practice their new role and gain insight into the recovery of the patient. Many of the families in our study had been separated from the survivor for several months. Upon coming home, even just for the weekend, families were re-united once again in their own homes. Although the weekend pass was overwhelming for the caregivers, many felt the emotional and physical rewards gained made the struggle worth enduring.

Caregivers in this study also expressed an increase in anxiety and fears before their first weekend pass. As the weekend passes progressed however, caregivers described feeling as though they were ‘getting easier’. Through repeated engagement in the weekend pass, many caregivers were able to dispel their anxiety and nervousness surrounding the transition home. However, in order to ensure such positive adjustment is experienced by all caregivers, health care professionals should help caregivers understand the benefits of experiencing a number of passes, and reassure caregivers that anticipatory anxiety is a common feeling. Without being comforted and informed, future caregivers may not understand the adjustment process, and forego additional weekend passes (as was seen with one caregiver in our study).

As a preliminary adjustment step, rehabilitation centers may consider adapting a simulated environment, such as a self-contained apartment within the institution. As Sife (1998) describes, many hospitals have begun to implement such “community-like stations” housed within the rehabilitation centers (Sife, 1998, p. 242). As he describes,
these environments have the advantage of providing community-like barriers and challenges, while in the protective environment of the hospital. In this way, caregivers, who are exceptionally anxious or doubtful, can be eased into the transition in smaller steps. Anxious caregivers may feel comforted knowing that if something went wrong over their first pass, that help was just a step away. In turn, caregivers may become more self-confident, and feel more active and in control of their discharge process.

*Having their Opinions Heard*

Positive engagement and communication between care recipients and care providers has long been reported in the literature as positively influencing health-care outcomes (Budd & Hughes, 1997). Similarly, communication with not only the care recipient, but the care recipients’ family can help post-stroke recovery. Caregivers in our study reported a need to be involved in their loved one’s care. Not only did they want to be communicated openly with, they wanted to be involved and engaged in decisions and the overall care process. Caregivers partaking in weekend passes began to understand that soon the full brunt of care would rest on them, and thus they craved membership in the care circle. Unfortunately, such involvement is not common practice in many rehabilitation hospitals (Visser-Meily, Post, Gorter, Berlekom, Van Den Bos, & Lideman, 2006). A recent study showed that only 4 to 20% of families are involved in the rehabilitation goals outlined for their own family stroke survivor (Monaghan, Channell, McDowell, & Sharma, 2005).

White et al. (2007) described a lack of communication between the family caregiver and the health care team as a barrier to undertaking and maintaining the
caregiving role. In our study, caregivers described feeling more comfortable when they were engaged and involved in their loved one’s care by the rehabilitation team. Thus, we may obtain a better outcome if stroke rehabilitation professionals more consistently involved families in the care of the stroke survivor. As described by Allen and Petr (1998) a family-centered approach would encourage care professionals who have primarily focused on the patient, to view the whole family as the unit of attention. In this way, illness information and care options would also be discussed with families (Allen & Petr, 1998). The sharing of such information would allow for a more comprehensive understanding of service decisions and future possibilities (Ellis-Hill et al., 2009). As a suggestion then, health professionals should consider inviting and encouraging family members to attend the stroke survivors’ rehabilitation sessions prior to the weekend pass. Such an opportunity may allow families and rehabilitation professionals to collaborate on important goals to be achieved before the pass (such as becoming comfortable navigating stairs together). Further, families could have a more realistic grasp on the stroke survivors’ disability before bringing them home for the first time. Through a more family-centered approach, health professionals can facilitate caregivers’ comfort, and ensure that all parties involved are working towards the same goals.

**Limitations & Future Research**

The limitations of this study need to be considered. As a primary consideration, all participants involved in this study were able to read, speak, and comprehend English. Thus, the results of this study may not be applicable to non-English speaking populations. Further, all participants were caring for stroke survivors who received inpatient therapy at
the same rehabilitation centre in a large urban setting. It is not clear if the experiences of caregivers caring for patients in other stroke rehabilitation units would experience weekend passes in quite the same way.

With regards to the methods used, the phenomenological interviews in this study were relatively short at approximately 15 minutes in length. This may be attributed to a novice interviewer, or to the caregivers’ inability to elaborate on such a personal topic at the time. Nonetheless, more time to establish rapport may have lead to a more in-depth interview and a greater glimpse into the lived experience of these caregivers. The issue of the location of the interview may also have been a limitation (for example, some caregivers felt guilty leaving their relative to participate in an in-hospital private interview). Similarly, although there is evidence to suggest that telephone interviews are comparable, and in some instances possibly even better, the inability to interpret non-verbal communication may also have been a barrier to an in-depth interview.

With regard to the sample population, not all participants in our study were able to complete the second of our interviews (4 caregivers were unreachable for a follow-up interview). This decline in involvement may be attributed to an increase in caregiver burden, and a decrease in caregivers’ available time to participate in such a research study. Inevitably, the caregivers with less demands, or more positive experiences, may have been more likely to complete our study.

Also worth noting, at the rehabilitation facility where recruitment took place, families and caregivers had the right to refuse the use of weekend passes. Perhaps not surprisingly, some families avoided weekend passes as they perceived going home, only to have to come back to the hospital, as a “tease.” Other families felt there was just too
much stress associated with the use of weekend passes. Because certain personalities and/or situations made it impossible for all rehabilitation consumers to use weekend passes, not all families at the rehabilitation centre could be approached for participation in this study. A future study may therefore consider examining families who refuse participation in weekend passes, and compare how adjustment in both populations differs.

Lastly, it is important to note that the present study is in no way seeking to comment on the appropriateness or quality of the services provided. Instead, we were looking to shed light on the experiences and perceptions of the individuals who used them. These perceptions are the opinions of each individual caregiver, and cannot be confirmed or denied. Though families may have received the usual preparation offered by the program, the data that I present reflects their perception of being prepared. Despite these recognized limitations, we believe that this study has provided a useful insight into what it means to be a caregiver throughout a weekend pass, and in this way, offers a foundation for future research and program development.

This study recommends investigation into the experiences of caregivers caring for other populations over a weekend pass, or from other care institutions in the future to observe whether populations beyond stroke would experience passes in similar ways. Research in the future should also investigate what effect providing our recommended support, and involvement to caregivers partaking in weekend passes has on the well being of caregivers, and the patients in their care. Continued research into the experiences of caregivers would provide a deeper understanding of this multidimensional and important topic.
**Conclusion and clinical implications**

This phenomenological study has examined the experiences of stroke family caregivers who participated in the weekend pass. The findings from this study can help health care professionals and service providers better understand the experiences of caregivers caring for a stroke survivor over a weekend pass. This knowledge may result in preparation and support that is more appropriate for individuals in this situation.

Our results underline the need caregivers feel to be involved in a loved one’s care. Health professionals should continue to work more closely with families to ensure the care of the patient, and family, is maximized. Health care professionals can do this by encouraging families to attend rehabilitation sessions with the stroke survivor, and encourage the use of family meetings with health professionals. Caregivers in our study also expressed adjusting to the weekend pass through its subsequent use. Therefore, health professionals should encourage families to practice their skills over a number of weekend passes, and reassure them that home passes continue to get easier as they progress. Further, caregivers in this study also perceived support from health professionals, family, and friends as aiding in the weekend pass process. To ensure all families have proper support in place, specialty services, such as social work, should evaluate each family situation prior to the first weekend pass. In this way, service providers can facilitate the comfort of all families, and offer additional support to families in need. Lastly, caregivers in our study perceived a number of benefits intrinsic in the weekend pass. By enhancing the support and preparation caregivers receive throughout
the weekend pass, benefits such as role preparation, opportunities for physical therapy, and emotional gains can be enhanced.

<table>
<thead>
<tr>
<th>Clinical Messages</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Healthcare professionals can maximize weekend pass benefits by ensuring caregivers are adequately prepared and feel supported throughout the weekend pass process.</td>
</tr>
<tr>
<td>o Specialty services such as social work, or family counseling should work together with families to decrease the overwhelming nature of the weekend pass.</td>
</tr>
<tr>
<td>o Further involvement with families in the rehabilitation process, and care of the stroke survivor can facilitate the comfort of caregivers, and the achievement of mutual goals.</td>
</tr>
<tr>
<td>o Caregivers should be encouraged to partake in more than one weekend pass, as the perceived benefits become more clear through its subsequent use.</td>
</tr>
</tbody>
</table>
CHAPTER 4

REFLECTIONS AND REMARKS

In this thesis I have discussed caregivers’ experiences with stroke survivors’ weekend passes. From this investigation, I have gained a better understanding of what it means to care for a stroke survivor throughout the weekend pass element of in-patient rehabilitation. However, through the course of this study, a few issues arose which deserve a final reflexive note, including the use of the phenomenological methodology, and a proposal on what I would do differently next time.

4.1 The Use of Phenomenology

Overall, I believe the value of a phenomenological approach to the study of caregiving was confirmed within this investigation. Phenomenology proved exceptionally useful, as it allowed me to capture caregivers’ experiences directly from their perspectives. Phenomenology also ensured that the translation of these experiences into research themes remained focused on the original meanings, as described by the caregivers themselves. This methodology contained several important steps to ensure the trustworthiness of the data. It is through these steps that I can be more confident that my results reflect the experiences of the participants involved.

By engaging in in-depth interviews on two separate occasions with the caregivers, I was able to build a level of trust with each participant. As the only researcher to conduct the qualitative interviews, I tried to make it easier for caregivers who were often very
emotional in telling their stories by listening carefully and validating their feelings where I could. Such open and honest discussions have confirmed my study’s credibility (the first criterion in a trustworthy study). This two-occasion interview style has also helped confirm the data’s dependability and stability.

Next, by attempting to practice a level of reduction throughout the interviews, and into the data analysis, I have increased the study’s confirmability and neutrality. For many people, the notion of reduction or bracketing is unachievable, for as some suggest, it may be impossible to liberate ourselves from any and all presumptions we carry with us into the field (Conklin, 2007). I agree with such a statement, but suggest that the elimination of all presumptions is not the true use of the phenomenological reduction. Instead, I believe, as previous phenomenological researchers have said, that the phenomenological reduction does not have to be absolute. Rather, the reduction should involve the simple consciousness of one’s presumptions (Conklin, 2007; Upton & Reed, 2006). In this way, throughout each interview, I questioned whether each of my interpretations were born from my presumptions of what it would be like to care-give, or whether something a particular caregiver said elicited the idea. Similarly, throughout the data analysis, I also consciously considered whether my interpretations did justice to the experience of the caregivers, if they were an accurate reflection of the data in front of me, or if they were born from my personal presumptions. Of course, I cannot be entirely sure that my reduction was absolute, but as per my interpretation, the conscious awareness of this helps to increase the study’s confirmability.

As a final consideration in the outcome of my results, interviews were conducted with 15 unique caregivers, all experiencing weekend passes. By interviewing 15
participants, from varying age groups, different genders, and differing relationships to the stroke survivor, the transferability of the study was enhanced. Thus, this study can hold true to the primary assumption of Edmund Husserl, in that the experiences described here may be transferable to other caregivers in the future.

Although the phenomenological approach has strengthened this qualitative study, several limitations may also have arisen from its use. First, the phenomenological interview process proved to be quite a challenge. In phenomenological studies, the interview is considered the main method of data collection. According to Jasper (1994), “the researcher using a phenomenological approach needs to develop specific skills to enable him/her to get to the lived experiences without contaminating the data.” Developing these interview skills in the context of data collection for this study yielded several unsound moments. For example, as I was trying to learn the fine balance between probing and not leading, I opted to ask very broad open-ended questions. This approach confused some participants, who commented, “I’m not sure what you mean, ask me some direct questions,” and “You have to point your questions a little more, I don’t know what you need to know.” In response, I tried to re-word my questions, or simply explain the fact that I was trying not to lead them. Some caregivers felt comfortable with this open approach, while others still struggled, suggesting they were not sure if what they were saying “was useful.” After some repeated exposure to the phenomenological interview this fine balance between probing and leading became clearer to me. In addition, some of the best advice I stumbled upon suggested the basic requirement for a successful phenomenological interview was simply the interest the researcher had in hearing others’
stories (Seidman, 1991). Knowing I was genuinely interested in hearing the caregivers’ stories boosted my confidence in my approach to the phenomenological interview style. Taking the time to learn such an approach may not have been feasible for all interviewers though.

Also, interview times in this study varied quite considerably. Some interviews lasted less than ten minutes, while other interviews lasted upwards of 45 minutes. This variation may be attributable once again to the participant’s comfort level with such an open-ended interview style, and my own unfamiliarity of when it was appropriate to probe further. After my first phenomenological interview, I wrote a reflexive journal note questioning whether this approach was indeed appropriate for caregivers at this stage of the recovery process. As a phenomenological researcher, I was hoping participants would ‘unravel’, whole-heartily expressing their innermost thoughts and experiences to me. Upon further reflection however, I realized caregivers at this stage in the recovery process may be doing their best not to unravel, and to maintain a strong front for their family members and the stroke survivor. Thus, the feasibility of such desired ‘candidness’ may not be possible at this stage in the care trajectory. Caregivers began opening up more honestly during the second interview, however I believe this was still not enough time for them to fully trust me as an interviewer, and to realize the full impact of their new caregiving situation. It may be appropriate for future studies to test the impact trust and time in the care continuum has on the openness of caregivers’ responses to a phenomenological interview. As an additional consideration, future caregiving studies may also choose to utilize home-based interviews as opposed to telephone or hospital-based interviews. By interviewing individuals in their own home, caregivers and
interviewers may build a greater rapport, and thus evoke more in-depth responses. However, future interviewers need to consider the burden this may place on caregivers opening their homes to researchers and weigh that against the potential for sharing additional perceptions.

A final comment on the phenomenological methodology involves the gathering of perceptions. At its root, phenomenology seeks to gain an understanding of an individual’s experiences based on their own perceptions of them. Because perceptions are reality to the individual, they must be treated as such. For example, if a caregiver reported not receiving support from the health care system in preparation for the weekend pass, whether or not they actually received it, we as researchers need to “hear” their perceptions of their experience. A key concept in qualitative research is the investigator’s understanding and interpretation of such perceptions. This may, in turn, represent a limitation of the phenomenological methodology to some as findings may not lead to clear cut implications for change.

Despite its complexity, the use of phenomenology proved to be an interesting process, through which I as a researcher gained abundantly. In my opinion, phenomenology continues to prove itself as a useful tool for health researchers, and is recommended to future researchers looking for a research methodology filled with both challenges and rewards.

4.2 What Would I Do Differently?

Overall, the present study has yielded positive results, and has been an encouraging research experience. However, if given the chance to start again, there are
three variables I may consider altering, including 1) using a different qualitative approach, 2) recruiting from multiple institutions, and 3) adding a third interview to the study design.

Although I feel the use of phenomenology was helpful in the present study, it may be interesting to see what results a different methodology may have produced. A specific change would concern the format of the interview questionnaire. A phenomenological questionnaire has relatively few open-ended questions and a series of probes (see appendix A). With a more direct methodology, such as a descriptive qualitative approach, a greater number of direct questions could have been asked. Such a change in the interview questionnaire may have resulted in both increases in interview length and variations in caregiver responses. Of course, abandoning the phenomenological approach for a more direct methodology may result in study conclusions which are more influenced by the researchers’ own personal assumptions which are seen in the choice of the directed questions. It may be worthwhile, however, to observe the extent to which such a change in methodology would influence my findings.

Next, all participants in the current study were caregivers of patients at one rehabilitation facility. It may have been valuable to recruit a select number of participants from a second rehabilitation institute, which also utilizes weekend passes. With this added participant group, I could observe if caregivers’ experiences at other institutions would have been similar. Such an adjustment to the recruitment procedure may have also yielded more transferable and/or trustworthy results. In addition, throughout the course of this study, it had been personally communicated to me that the rehabilitation facility used
in the current study constantly receives a higher satisfaction rating from its clients when compared to other rehabilitation institutes in the area. It stands that caregivers from other facilities with lower satisfaction ratings may have greater needs, and/or more negative experiences. By recruiting outside of a single facility, I could have controlled for such a bias.

Lastly, it may have been interesting to append a third interview to my study, further along in the caregiving trajectory. As mentioned earlier, caregivers began to open up more sincerely during the second interview. It may be assumed that the interview/interviewee relationship would have continued to build, yielding a longer and more open third interview. Additionally, caregivers in our study may not have had the chance to fully reflect on the impact of their new role as caregiver. For example, one caregiver in our study chose to take her first two weeks off from work to stay home with the stroke survivor as they were adjusting to being back in the home together. Thus, during our second interview, this caregiver had not yet experienced her typical everyday routine, wherein she would need to balance work and caregiving. In such circumstances the caregiver has not yet understood the full impact that caregiving may have on her everyday life. Interviewing caregivers 6-months into their caregiving careers may have provided a more comprehensive insight into their experiences, and how weekend passes may or may not have influenced their longer-term adjustment.

In summary, although the outcome of the study has been deeply informative, the aforementioned changes may have furthered the usefulness of this study.
The transition home has been described as one of the most difficult transitions facing stroke survivors and their family caregivers (Turner et al., 2007). Weekend passes represent an opportunity to help prepare patients and caregivers for this transition, yet until this study, there had been no investigation of the experiences of the individuals involved. That means, services such as weekend passes were developed and implemented by health professionals based primarily on their own understanding of the process (Ellis-Hill et al., 2009). With the knowledge imparted by this phenomenological study, we will have a more subjective understanding upon which to build future services. It has been proposed that while the phenomenological approach may elucidate a sense of life-world meaning, its real purpose and value lie in enabling health professionals to establish a sense of ‘shared understanding’ with their patients (Munhall, 1994). In this way, I hope the results of this study can inform healthcare professionals, hospital administrators, and support staff of the needs and experiences of caregivers. Through this shared understanding, the transition home can move from a time filled with stress, to a promising step in the road towards recovery.
REFERENCES


behavioral and psychological symptoms are associated with informal caregivers’ experiences of depression. *Archives of Physical Medicine & Rehabilitation, 87*, 177-183.


intervention: results of a randomized controlled trial. *Archives of Internal Medicine, 166*, 1822-1828.


Ellis-Hill, C., Robison, J., Wiles, R., McPherson, K., Hyndman, D., & Ashburn, A.


Lewis, M., Trypuc, J., Lindsay, P., O’Callaghan, C., & Dishaw, A. Has the Ontario Stroke System really made a difference? *Healthcare Quarterly, 9*, 50-60.


*Journal of Clinical Nursing, 17,* 2497-2508.


*Journal of Neuroscience Nursing, 39,* 172-178.


Turner, B., Fleming, J., Cornwell, P., Worrall, L., Ownsworth, T., Haines, T., Kendall,


Family Caregiver Interview Questions

Interview Guide:

Family Caregivers:
Throughout this interview I would like you to share with me your experiences with your family member’s weekend passes home. I would like you to share your feelings about, ideas of, and experiences with, weekend passes as best you can. Please think not only about your care-giving activities but also how your experience affected other aspects of your life.

Interview Questions:

**Interview 1 – Within one week after the first scheduled weekend pass:**

1. Your family member has had a stroke, can you please share with me [insert stroke survivor name or relationship here]’s “stroke story,” describing the journey from the initial symptoms of the stroke, up until this point.

2. [Stroke survivors’ name] recently came home for the weekend on a weekend pass. Can you describe your experiences with the weekend pass to me in your own words? (ie. share with me your “weekend pass” story).

   The following series of probes will be used to elicit further information regarding family caregivers experiences, and will be used on a semi-structured basis in accordance with what each caregiver chooses to discuss:

**Probes:**

   o What were you feeling before you took your loved one home? (ex. anticipation, nervousness, etc.).
What information, training, and or support did you receive in regards to the weekend visit? When was it received? How? From who? Was it helpful or unhelpful? Why?

How and where would you like to have received this information, training, and/or support?

Can you please describe how you got your loved one home? What was that experience like? How did it feel to have your loved one at home with you?

Did anyone help you, or provide assistance in caring for the stroke survivor over the weekend? If so, please describe what they did.

Please tell me about your experiences after the weekend pass concluded, and the patient returned to the hospital.

What follow-up evaluations were taken? By who? How?

Were you offered any information, training, and or other supports when bringing the stroke survivor back at the inpatient facility?

Did you have any unmet needs for information, training, and/or support at this time?

What were your thoughts as you were preparing to bring the stroke survivor back to the Rehabilitation hospital?

How was the timing of the first weekend pass? Too early, just right? Why?

Do you have any other comments or concerns about your family member’s weekend pass?

Do you have any final thoughts at this time about the weekend pass program?

---

**Interview 2 – Two-weeks following final discharge home:**

1. Can you please describe how [stroke survivors’ name] is doing now? (ie. please share with me your ‘continuing stroke story’).
2. Can you please describe to me in your own words your experiences with the last few home passes?

3. Now that [stroke survivors’ name] is home, how has this transition (moving from in-patient rehab to home) been like for you?

The following series of probes will be used to elicit further information regarding family caregivers experiences, and will be used on a semi-structured basis in accordance with what each caregiver chooses to discuss:

**Probes:**

- How many times did the stroke survivor come home on weekend visits in total? How did the experience of the second and third home visit compare to the first home visit?
- Were you offered any additional support (i.e. informational, training, and/or emotional, etc.) between your first home visit and consecutive home visits? From who? How? When?
- Did you feel better prepared for the subsequent home visits as compared to your first experience with home visits?
- Looking back, what are your thoughts on the weekend pass program? Was the experience beneficial to you? Detrimental to you? Please discuss your feelings with the overall process.
- Do you think the weekend pass experience helped prepare you and the stroke survivor for your eventual transition home? Did this experience make the transition from in-patient rehabilitation to the home environment easier?
- Do you perceive any areas for improvement in the weekend pass program?
- As you now reflect or think back on your experiences with weekend visits, what benefited you the most throughout the experience?
- Do you have any final thoughts at this time about your weekend pass experience?
To help us better understand the entire transition, and how caregivers would like to be involved, we have developed the following questions to be incorporated into the interview:

4. Thinking back over your family members stay in the different health care environments (acute care, rehabilitation, etc.), how were you involved, and how would you like to have been involved in your loved one’s care?

**Probes:**
- Involvement with healthcare professionals?
- Involvement in stroke survivor care?
- Do you perceive any benefits coming from this involvement? Do you perceive any negative consequences coming from this involvement?
- Do you feel you were incorporated as much as you would have liked to have been on decisions and information regarding your family members care?

5. Would you like to be considered a member of your family member’s health care team? What are the advantages and disadvantages you see coming from this “official” status? Can you describe to me what such a role (as an official health care team member) would look like to a family caregiver?

**Probe:**
- What areas of care do you see yourself more involved in?
- Who would you primarily interact with?
Appendix B
October 8, 2008

Dr. Jill Cameron
Toronto Rehab and University of Toronto
540 University Avenue, Suite 100
Toronto, ON M5G 1V7

Dear Dr. Cameron:

RE: TRI REB # 08-003
The Weekend Home Visit Program During Inpatient Rehabilitation: How can we Optimize the Benefits to Stroke Survivors and Family Caregivers?

The Toronto Rehabilitation Institute Research Ethics Board has reviewed the above-named submission. Any concerns and requested revisions have been addressed to the satisfaction of the REB. The protocol (June 1, 2007) is approved for use for the next 12 months. If the study is expected to continue beyond the expiry date, you are responsible for ensuring the study receives re-approval. The REB must also be notified of the completion or termination of this study and a final report provided.

The following documents are also approved:
- Family Caregiver Consent Form, updated, as received July 10, 2008
- Health Care Professionals Consent Form, version September 10, 2008
- Patient Consent Form, version September 10, 2008
- Family Caregiver Interview Questions, updated, as received July 10, 2008
- Health Care Professional Interview Questions, updated, as received July 10, 2008
- Patient Interview Questions, updated, as received July 10, 2008

If, during the course of the research, there are any serious adverse events, changes in the approved protocol or consent form or any new information that must be considered with respect to the study, these should be brought to the immediate attention of the REB.

Best wishes for the successful completion of your project.

Yours sincerely,

[Signature]

[First Name] [Last Name] MD FRCP(C)
Chair, Research Ethics Board
Toronto Rehabilitation Institute

[First Name] [Last Name] PhD
Vice Chair, Research Ethics Board
Toronto Rehabilitation Institute

October 6, 2008
Date of Initial REB Approval

October 6, 2008
Expiry Date of REB Approval

TRI REB conforms with the Tri-Council Policy Statement Ethical Conduct for Research Involving Human Subjects (March 2010)
Appendix C
Informed Consent Form for Participation in a Research Study

Family Caregiver Consent Form

STUDY TITLE: The Weekend Home Visit Program during Inpatient Rehabilitation: How can we Optimize the Benefits to Stroke Survivors and Family Caregivers?

INVESTIGATOR: Jill Cameron, PhD

You are being asked to take part in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the proposed study procedures. The following information describes the purpose, procedures, benefits, discomforts, risks and precautions associated with this study. It also describes your right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask the study investigator or study staff to explain any words you don’t understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before signing this document.

Purpose
The purpose of this study is to gain insight into the experiences of patients, as well as family caregivers, and health professionals in order to better understand weekend home visits from in-patient rehabilitation.

Objectives
To determine what the experiences are of family caregivers and stroke survivors partaking in weekend visits from in-patient rehabilitation. We hope to learn more about what resources are being provided, as well as determine what caregivers’ and stroke survivors’ needs for further information, training, and/or support are. We hope this information will ultimately help us optimize the transition from in-patient rehabilitation.
to the home environment. Approximately 15 caregivers are expected to participate in the study.

**Procedures**
If you decide to participate in this study, you will participate in two interviews. The interviews may take place in-person, at Toronto Rehabilitation Institute, or over the telephone at your convenience. We hope to gain insight from you directly following the first home visit, and then again once you have had time to adjust to living back at home with your family member. Thus, the first interview will take place the week following your family member’s first home visit. The second interview will take place around 2 weeks after your family member’s final discharge home. Interviews will last between 30 and 90 minutes. You will have the right to not answer any question, or simply ask to ‘pass’ any particular question you are not comfortable answering. The discussion portion of the interview will be audio tape-recorded so that the researchers can look back at your responses accurately, and use them to help us better understand caregivers’ experiences with weekend visits.

**Risks**
Caregivers participating in our study will be asked to reflect on their experiences, emotions, and preparedness for caring for a strike survivor post-stroke. There is a possibility that the interview may be upsetting as you think of your experience and the future. The researchers are prepared to help participants confronting difficult emotional issues by directing such participants to qualified professionals, and by providing participants with relevant references/information. There are no other significant risks to participating in this study.

**Benefits**
You may benefit from expressing your experiences, emotions, and concerns to an attentive listener. Although you may not directly benefit from the results of this study, you may benefit from knowing that your experiences may help other caregivers experiencing weekend visits in the future.

**Confidentiality**
The information that is collected for the study will be kept in a locked and secure area by the study researchers for 7 years. Only the study team or the people at The Toronto Rehabilitation Research Ethics Board will be allowed to look at these records.

Any information about you that is sent out of the hospital (Example: to be used in scientific presentations, conferences, or published papers) will have a code and will not show your name or address, or any information that directly identifies you.

All information collected during this study will be kept confidential and will not be shared with anyone outside the study unless required by law.
If you decide to leave the study, the information about you that was collected before you left the study will still be used. No new information will be collected without your permission.

**Participation**
Your participation in this study is voluntary. You can choose not to participate or refuse to answer a question, or withdraw at any time without penalty or loss of benefits to you or to the person you are caring for.

**Compensation:**
In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities. There are no costs associated with participation in this study. You will not be compensated for time or travel costs associated with study participation.

**Questions**
If you have any general questions about the study, please call investigator Dr. Jill Cameron at 416-597-3422 ext. 2126.

If you have any questions about your rights as a research participant, please call the Toronto Rehabilitation Ethics Board at 416 597-3422, ext. 7611. These individuals are not involved with the research project in any way and calling them will not affect your participation in the study.

**Consent**
I have had the opportunity to discuss this study and my questions have been answered to my satisfaction. I consent to take part in the study. I may withdraw at any time without affecting the medical care of my loved one. I have received a signed copy of this consent form. I voluntarily consent to participate in this study.

---

**Participant’s Name (Please Print) __________________ Participant’s Signature __________________ Date __________________**

I confirm that I have explained the nature and purpose of the study to the person named above. I have answered all questions.

---

**Name of Person __________________ Signature __________________ Date __________________**