

THE RELATIONSHIP BETWEEN FAMILY CAREGIVERS' EMOTIONAL STATES AND
ABILITY TO EMPATHIZE WITH POST-STROKE INDIVIDUALS

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A Thesis submitted to the Faculty of Graduate Studies of
The University of Manitoba
in partial fulfillment of the requirements of the degree of

MASTER OF NURSING

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ACKNOWLEDGMENT

I would like to thank many people without whose input and support this thesis project would not have been possible.

I sincerely appreciate all caregivers who agreed to participate in this study, for their willingness to share their experiences with me, which can be a very difficult part of their lives. I was inspired by the strength and wisdom of all the participants.

I would like to extend my sincerest thank to each of my committee members for their contribution to this study. I take this opportunity to express the deepest appreciation to my committee chair Dr. Michelle Lobchuk, for her dedication, guidance and support. The last three years have been challenging, yet enriching, and I have learnt a great deal from her. She has always been available to support me, push me and encourage me, and for that I am always indebted. Without her support and persistent help this thesis would not have been made possible. I would like to express my appreciation my committee member, Dr. Wanda Chernomas, without her knowledge and invaluable assistance this study would not have been successful. In addition, special thanks to Dr. Sepideh Pooyania, who introduced me to Post-stroke Outpatient Clinic, without her assistance and guidance this study would not have been successful.

I would like to warm thanks to Ms. Elsa Critchlow, Mr. Russ Down for your kind help in recruitment process, despite their busy schedule. I would like to thank Mr. Jim Sinclair, your enthusiastic and dedication about assisting post stroke individuals and their families will continue to inspire me as I continue my work in the field of nursing.

I wish to express my gratitude to Dr. John Bond, Dr. Judith Scanlan, Mr. Malcolm McKenzie, Ms. Maggie Bowman, Ms. Cosette Taylor and Ms. Hazel Rona, who were abundantly helpful and offered valuable support.

I would like to express my wholehearted thanks to my unit manager Ms. Sheila Tagesen in GH4 in Health Science Centre, all friends from GH4 and graduate class, for your encouragement and endless support. I would also like to convey my thanks to the Manitoba Nurse Union Local 10, Foundation for Registered Nurses of Manitoba, their financial support allowed me to focus uninterrupted on my studies and was incredibly helpful.

I would like to acknowledge the tremendous support of my family. Thank you to my mother, father and brother for their unconditional love and support, always believing in me, and always being there when I needed them. And thanks to my husband's constant support, understanding, encouragement and for helping me in each and every situation.

To all of the above, thank you! I would not have done it without you!

ABSTRACT

Stroke is one of the most prevalent chronic illnesses in Canada. Family caregivers can make a significant contribution toward patients' recovery. Caregivers' emotions can impact their motivation to engage in empathy-related helping behaviours. The purpose of this study was to examine relationships among functional deficits of post-stroke individuals, family caregivers' emotions, and caregivers' ability to empathize with post-stroke individuals. As guided by Davis's organizational model on empathy, a correlational descriptive methodology was employed. Participants were requested to complete four questionnaires. Study found that caregiver fatigue was the only factor associated with caregiver empathy-related behaviour. Analyses also found that communication deficits had a linkage with caregivers' negative emotions. Study results will contribute to the current state of the literature on post-stroke care at home by understanding of the impact of caregivers' psychological experiences on their empathy-related responses toward post-stroke individuals. Recommendations for clinical practice and future research were made based on this study's results.

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CHAPTER ONE: STATEMENT OF THE PROBLEM

Introduction

A stroke is a sudden loss of brain function. It is caused by the interruption of flow of blood to the brain (ischemic stroke) or the rupture of blood vessels in the brain (hemorrhagic stroke) (Heart and Stroke Foundation, 2009). About 80% of strokes are ischemic, caused by the interruption of blood flow to the brain due to a blood clot. About 20% of strokes are hemorrhagic, caused by uncontrolled bleeding in the brain. The interruption of blood flow or the rupture of blood vessels causes brain cells (neurons) in the affected area to die (Heart and Stroke Foundation, 2009). The effects of a stroke depend on where the brain was injured, as well as how much damage occurred. A stroke can have an impact on any number of areas including the ability to move, see, remember, speak, reason, read, and write (Heart and Stroke Foundation, 2009).

According to the statistics in the Internet Stroke Centre (ISC) (2000), 15 million people suffer stroke worldwide each year. Of these, five million die and another five million are permanently disabled (ISC, 2000). Stroke is the third leading cause of death and the leading cause of adult disability resulting in admission to long-term care facilities in Canada (Lindsay et al., 2010). Each year, approximately 300,000 Canadians suffer a ‘brain attack’ that will lead to death or serious disability: seven per cent are 75 years old or older (Public Health Agency of Canada, 2009). Hereafter, the researcher will alternate between “post-stroke individuals”, “patients”, or “person/people” (with stroke) in reference to individuals who have suffered a stroke.

Many people with stroke face physical and mental challenges that greatly affect their quality of life. As many as 300,000 survivors live with stroke, but it has been estimated that 29%

of individuals who experience a stroke die within a year, 20% die within three months, 25% become dependent, and 46% remain independent (Hankey & Warlow, 1999). While stroke can be distressing for the patient, its impact does not end there. The condition also has an enormous effect on the patient's family. Most patients will need help to perform basic daily activities, such as dressing and personal hygiene. For the family caregiver, sudden changes in the family lifestyle and a sense of isolation can cause depression and anxiety (Canadian Stroke Network, 2009). One year after a stroke in their family member, 50 per cent of caregivers develop an emotional illness (Canadian Stroke Network, 2009). As fewer than 50 per cent of stroke patients can return to work, families carry the additional burden of lost income (Canadian Stroke Network, 2009). In addition to its social effects, strokes drain the Canadian economy. The Public Health Agency of Canada (2009) reported that there are 300,000 individuals living with the effects of stroke in our country. With stroke being a leading cause of death and disability, estimated costs associated with stroke stand at \$3.6 billion in health care costs and lost economic gains due to hospital cost and long-term disability (Public Health Agency of Canada, 2009). Resources include direct medical costs such as emergency services, hospitalizations, rehabilitation, physician services, diagnostics, medications, allied health professional services, homecare, medical/assistive devices, changes to residence, and need for paid caregivers. However, there are many indirect costs as well, such as lost productivity due to mortality and long or short-term disability (Statistics Canada, 2009).

Stroke is the second largest contributor to hospital care costs among cardiovascular diseases (Heart and Stroke Foundation, 2009). It is known that seniors account for the greatest number of stroke patients. According to the 2001 Census (Statistics Canada, 2008), seniors aged 65 years and over constituted 13% of the Canadian population. This proportion is projected to

reach 15% by 2011 and just over 20% by 2025 (Statistics Canada, 2008). All these figures show the significance of stroke prevention and post stroke care. Post stroke care places a financial and emotional burden on associated individuals, families, and society. With up to 80% of stroke survivors returning to the community (Anderson, Linto, & Stewart-Wynne, 1995), the support of family caregivers plays a key role in the swift recovery and rehabilitation of patients.

The disability of a post stroke individual affects the entire family. Families face enormous stress due to the physical, emotional, and psychological consequences of stroke, which often constrain their social roles, activities (Clarke, Black, Badley, Lawrence & Williams, 1999), and reduce the quality of life (QoL) of both stroke survivors and their families (Bugge, Alexander & Hagen, 1999). Negative emotions (e.g., anger) of patients and/or caregivers were also found to mediate the effect of symptom severity on stress proliferation (Benson, & Karlof, 2009). Although the burden of caregiving has been observed to affect family members' physical and psychological well-being, and quality of life (Canam & Acorn, 1999; King et al., 2001), caregivers of stroke patients have also reported satisfaction with their lives and have expressed positive feelings about their roles and abilities to cope with the consequences of stroke (Hackett, Duncan, Anderson, Broad, & Bonita, 2000; Willeke, Kruithof, Johanna, Visser-Meily, Marcel, 2012). These conflicting observations indicate a great need for more detailed study of emotional changes in family caregivers when they respond to and cope with the consequences of stroke and resulting disability. As nurses, we can better understand the varied roles of family caregivers, assist family caregivers to provide effective support for their loved ones, promote the empathic caregiving relationship, and further help in improving the quality of life of the entire family after the stroke event.

Statement of the Problem

In light of our aging population, and growing chronic illness in western society, increasing numbers of family members have primary responsibility for providing care to affected individuals. Stroke is one of the most prevalent chronic illnesses in Canada (Family Caregiver Alliance, 2012). Family caregivers can make a significant contribution to their loved one's recovery. Deciding to take on the responsibilities of being a caregiver can bring about a variety of emotions. As circumstances of the caregiving role change over time, so can the caregiver's emotions. There is a need to better comprehend the caregiver's helping responses to the individual dealing with post-stroke. The literature on family caregiving indicated that emotions can be positive or negative, and can range from joy, hope, anger, and depression to guilt (Folkman & Moskowitz, 2000). Most caregivers may not want to talk about or acknowledge negative feelings, due to social expectations about family responsibility to engage in the caregiver role. Fear and anxiety are common in families when their loved one's physical or mental condition is declining and safety is at risk (Brandt, 2000). With overwhelming emotional changes, frustration can occur. Frustration may occur due to the lack of cooperation from affected loved ones, family and friends, the medical community, or perceptions of putting in a lot of effort with very little in return to the family caregiver. Frustration may lead to resentment toward the affected individual, families, friends, and even professionals who do not seem to help the family caregiver or who have free time and appear to be relatively unburdened by demands in the caregiver role. Frustration and resentment are the foundation of anger (Schoenmakers, Buntinx, & Delepeleire, 2010). In the process of caregiving, the caregivers' physical and psychological factors can contribute toward caregiver burden. Caregivers may be more aware of their own mortality, making them feel more vulnerable. Other researchers have found that angry

or resentful caregivers of post-stroke patients reported feeling more burdened than those caregivers who did not express anger (Thompson, Medvene, & Freedman, 1995). Moreover, angry caregivers tended to engage in less empathic responses toward care recipients (Lobchuk et.al, 2008).

Purpose

The purpose of this study is to identify and assess relationships among functional deficits of individuals dealing with post-stroke, the family caregiver's emotions (psychological distress), and family caregivers' ability to empathize with post-stroke individuals.

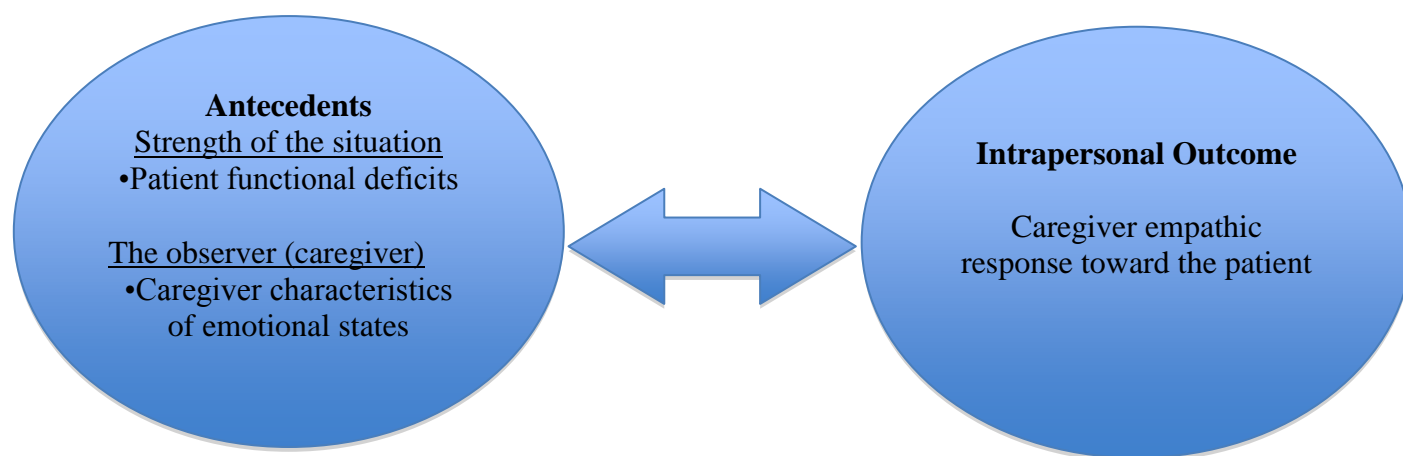
Theoretical Perspective

Davis's (1994) empathy organizational model provided a guiding framework for this researcher's examination of potential relationships among patients' functional deficits, the caregiver's emotional or psychological states, and the caregiver's empathy toward to the post stroke individual. The researcher adapted part of the model to represent relationships among key study variables. Figure 1 (next page) provides a graphical illustration of this study's conceptual framework that was adapted from Davis's (1994) organizational model of empathy.

As guided by Davis's (1994) model, the family caregiver often serves as a witness to the suffering or distress of an individual dealing with post stroke. Depending on the 'strength of the situation' experienced by the individual dealing with post stroke, different responses such as empathic processes in the family caregiver might be evoked. The 'strength of the situation' is defined as one type of antecedent variable that can elicit an empathic response in the family caregiver toward the individual dealing with post-stroke. In this study, the patient's functional deficit level after stroke represents one type of antecedent variable (situational variable) that can have a direct relationship to the caregiver's empathic response toward the patient. A second

antecedent variable in this study will be represented by the caregiver's emotional or psychological status (e.g. anger) that can also evoke an empathic response in the caregiver toward the patient.

Figure 1. Adapted empathy model from Davis's (1994) Empathy Organizational Model



As guided by Davis' (1994) model, both the patient's functional deficit level after stroke and the caregiver's emotional or psychological state have potential to be associated with intrapersonal processes in caregivers. One such intrapersonal process experienced by family caregivers in response to the patient's functional deficits and the caregiver's emotional or psychological state might be an empathy-related response. Empathy-related processes are defined as demanding cognitive processes that involve imagining the patient's perspective on the situation to better understand the patient (Davis, 1994). Davis (1994) further described that, as a result of these empathic processes, interpersonal outcomes such as helping behaviours by the

caregiver toward the patient may occur. In this study, the researcher will aim to examine relationships of two antecedent variables (patient functional deficit level and caregiver emotional or psychological state) with the intrapersonal outcome, the caregiver's empathic response toward the individual dealing with post-stroke.

Independent and Dependent Variables in this Study

In this study, the patient's functional deficit level and the caregiver's emotional or psychological state are the independent variables. The family caregiver's empathy-related response toward the patient is the dependent variable for this study. As guided by Davis' (1994) organizational model on empathy, the caregiver's emotional or psychological status and the patient's functional deficit level can both directly affect the caregiver outcome of empathy-related responses toward the patient. In this study, the researcher aimed to attain a better understanding of the potential relationships among the caregiver's empathic responses toward the patient, the patient's functional deficit level, and the caregiver's emotional or psychological state within the context of caring for patients dealing with post-stroke in the home.

Operational Definitions of the Research Variables

This study used Davis's empathy organization model as a guide to examine relationships among the patient's functional deficit level, the caregiver's psychology or emotion state, and the caregiver's empathy-related response. The following definitions were established to convey understanding of the concepts in this study. These definitions will be described more fully in the literature review section found in the next chapter.

Functional deficit refers to physical and mental or emotional functional decline due to the consequences of the stroke event (Ware, Kosinski, & Dewey, 2000). The functional deficit of the

post stroke individual was measured by the Stroke Impact Scale's proxy version: caregivers provided their perspectives of the post-stroke individual's functional deficits with this tool.

Psychological distress was measured as the Total Mood Disturbance score in the Profile of Mood States short form (Heuchert & McNair, 2012). The Total Mood Disturbance score indicated mood disturbance, emotional or psychological distress or subjective well-being by capturing and evaluating fatigue, vigor, tension, depression, anger, friendliness, and confusion (Heuchert & McNair, 2012). The Profile of Mood States built on several studies of emotional disturbances and psychopathology (e. g. Berenbaum, Raghavan, Vernon, & Gomez, 2003). According to Berenbaum et al. (2003), emotional disturbances are divided into three types, including too many or too few pleasant or unpleasant emotions, intensity/regulation, and disconnection of emotion. There were several disorders described that involve emotional disturbances, such as mood and anxiety disorder, and disorders with symptoms of emotion disturbance, such as schizophrenia (Johnson et al., 2009), and insomnia (Harbey, McGlinchey, & Gruber, 2009). In addition, there were a number of disorders with emotion-related disturbances, such as excess of emotion, deficit in emotion, mismatches between the expression and experience of emotions, and deficits in social emotions, could also evaluated by Profile of Mood states (Berenbaum et al., 2003).

The caregiver's empathy-related response is defined as his or her internal, cognitive responses that reflect his or her attempts at understanding, being aware of, being sensitive toward, or vicariously experiencing the feelings, thoughts, and experiences of the patient. The caregiver's awareness of the patient's feelings, thoughts, and experiences is not necessarily communicated in an objectively explicit manner (O' Brien & DeLongis, 1990). The caregiver's

self-report on his or her empathy-related response toward the patient was evaluated by the Empathic Responding Scale (O' Brien & DeLongis, 1990).

Research Questions

The following questions were addressed in this study.

1. What is the relationship between the patient's functional deficits and the caregiver's emotional or psychological states?
2. What is the relationship between the caregiver's emotional or psychological states and the caregiver's empathy-related helping behaviour?
3. What is the relationship between the patient's functional deficits and the caregiver's empathy-related helping behaviour?
4. Are the patient's functional deficits and the caregiver's psychological or emotional states predictive of the caregiver's empathy-related helping behaviour?

Significance of the Study

The results of this study will contribute to the current state of the literature on post-stroke care at home by providing an increased understanding of the psychological or emotional experiences of the caregivers of post stroke individuals. Specifically, this study will focus on the patient's functional deficit level and the caregiver's psychological or emotional state in association with the caregivers' ability to empathize with post-stroke individuals. If evidence is found to support, for example, a negative linkage between the caregiver's negative emotional states and the caregiver's empathy-related responses toward the post-stroke patient, then future empirical work can devise and test interventions that minimize the caregiver's negative emotions

or the impact of these emotions on the caregiver's motivation to engage in empathy-related responses toward individuals with dealing with post-stroke.

CHAPTER TWO: LITERATURE REVIEW

Introduction

The purpose of the literatures review was to identify previous research and explore the current state of knowledge regarding relationships among the functional deficits of persons with stroke, caregivers' emotional status, and caregivers' empathic responses. The following review of the literature helped the researcher to comprehend the caregiver's situation when assisting a loved one with stroke to manage his or her condition. The researcher's review of the literature was organized under four main headings: i) pathophysiology of stroke; ii) patient's deficits after stroke; iii) caregiving experiences (characteristics of persons with stroke and family caregivers); and, iv) empathy in family caregiving. Each area of the literature was discussed below under separate sub-headings.

As part of the study, a detailed literature search for relevant articles was undertaken using electronic library searches and search engines (PUB-MED, CINAHL, Cochrane Collaboration, and PsycINFO, EMBASE, Scopus, Google search). Family caregivers' (hereafter simply called 'caregivers') emotions and their ability to empathize with persons with stroke (hereafter referred to as either post-stroke "individuals" or "patients/ person" with stroke) were the main concepts of the study. The functional deficits of persons with stroke were also explored in the literature as a potential trigger that is associated with caregivers' emotions and empathic response. Thus, the key words of "stroke", "family caregivers", "emotions", and "empathy" were employed in a computer search of the literature.

Pathophysiology of Stroke

According to the statistics of the Internet Stroke Centre (ISC), 15 million people suffer stroke worldwide each year. Of these, five million die and another five million are permanently disabled (ISC, 2000). Stroke is the third leading cause of death in Canada (Statistics Canada, 2009; Lindsay et al., 2010). Each year, approximately 50,000 Canadians suffer a 'brain attack' that will lead to death or serious disability, and nearly 14,000 Canadians die from stroke (Statistics Canada, 2009).

Many individuals with stroke face physical and mental challenges that greatly affect their quality of life. As many as 300,000 survivors live with the knowledge that they have a 20% chance of having another stroke within two years (Statistics Canada, 2009). After the age of 55 years, the risk of stroke doubles every ten years (Heart and Stroke Foundation, 2008). Only ten percent of people with stroke can achieve complete recovery; others might be affected by a range of outcomes from minor disability to death (Heart and Stroke Foundation, 2008). The effects of a stroke depend on which part of the brain is injured, and how severely it is injured. Strokes may cause sudden weakness, loss of sensation, or difficulty with speaking, seeing, or walking (Heart and Stroke Foundation, 2008). Since different parts of the brain control different areas and functions, it is usually the area immediately surrounding the stroke that is affected. Sometimes individuals with stroke have a headache, but stroke can also be completely painless (Lezak, 2004). Therefore, it is very important to recognize the warning signs of stroke and to get immediate medical attention if they occur.

Definition and Types of Stroke

A cerebrovascular accident (CVA), commonly known as a stroke, is the most common form of cerebrovascular disease, particularly in people aged 65 years and older (Lezak, 2004). A

stroke “is caused by a sudden interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot” (Adams, Victor, & Ropper. 1997; WHO, 2001).

When a stroke event occurs, the disruption stops vital nutrients oxygen and glucose from reaching brain cells, leading to irreversible tissue damage (Lezak, 2004; WHO, 2001). Stroke is not one syndrome with uniform causes or outcomes (Frizzell, 2005). The use of modern brain imaging technology (e.g. Computer Tomography or Magnetic Resonance Imaging) has allowed stroke to be categorized into different types (Lezak, 2004). A stroke should be distinguished from a Transient Ischemic Attack (TIA) which is defined as a transient episode (symptoms persist for <24 hours) of blood flow disturbance without resulting tissue death (Easton et al., 2009) or long-term impairment (Lezak, 2004). There are two major types of stroke: ischemic stroke and hemorrhagic stroke. About 80% of strokes are ischemic strokes caused by the interruption of blood flow to the brain due to a blood clot (Heart and Stroke Foundation, 2008; Warlow, Sudlow, Dennis, Wardlaw & Sandercock, 2003).

Ischemic Stroke. The ischemic stroke may happen in two ways. A clot may form in an artery that is already very narrow, which is called a thrombotic stroke (Adams et al., 1993; Lezak, 2004; Heart and Stroke Foundation, 2008). Thrombotic strokes occur when plaque-like deposits of cholesterol build up and grow along the arterial walls causing arteries to narrow or become blocked, disrupting blood flow to the brain, especially via arteries in the neck to the brain (Adams et al., 1993; Lezak, 2004). This atherogenic process leads to the condition called atherosclerosis, i.e., the condition of thickened arterial walls (Tegos, Kalodiki, Sabetai & Nicolaides, 2001). This subtype accounts for about 40% of all stroke cases.

Another type of ischemic stroke is called embolic stroke in which a clot may break off from another place in the blood vessels of the brain or from some other part of the body, and

travel up to the brain to interrupt the blood flow (Heart and Stroke Foundation, 2008). This subtype accounts for about 16% of all stroke cases (Warlow et al., 2003).

Ischemic stroke may be caused by clogged arteries caused by fat, cholesterol, and other substances which collect on the artery walls, thereby forming a sticky substance called plaque (Heart and Stroke Foundation, 2008).

Hemorrhagic Stroke. Twenty percent of strokes are hemorrhagic, which occur when a blood vessel in a part of the brain becomes weak and bursts open, and causes blood to leak into the brain (Heart and Stroke Foundation, 2008). Some individuals have defects in the blood vessels of the brain that make this occurrence more likely. There are two kinds of hemorrhagic stroke. Intracerebral (within the brain) hemorrhage occurs when a diseased blood vessel within the brain bursts which allows blood to leak inside the brain (Donnan, Fisher, Macleod, & Davis, 2008; Lezak, 2004). The sudden increase in pressure within the brain can cause damage to the brain cells surrounding the blood (Lezak, 2004). If the amount of blood increases rapidly, the sudden build-up in pressure can lead to unconsciousness or death (Lezak, 2004). Intracerebral hemorrhage usually occurs in selected parts of the brain, including the basal ganglia, cerebellum, brain stem, or cortex (Chung & Caplan, 2007), accounting for 15% of all stroke cases (Warlow et al., 2003).

Subarachnoid hemorrhage occurs when a blood vessel ruptures just outside the brain. The area of the skull surrounding the brain (i.e., the subarachnoid space) rapidly fills with blood (Chung & Caplan, 2007; Donnan et al., 2008; Lezak, 2004). A patient with subarachnoid hemorrhage may have a sudden, intense headache, neck pain, and nausea or vomiting. Sometimes this hemorrhage is described as the worst headache of one's life. The sudden build up

of pressure outside the brain may also cause a rapid loss of consciousness or death (Chung & Caplan, 2007). This subtype accounts for 5% of all stroke cases (Warlow et al., 2003).

Risk Factors

There are non-modifiable and modifiable risk factors for all types of strokes. The non-modifiable risk factors are age, gender, genes, disease, physiological condition, and reproductive period. The risk of stroke increases with age (Heart and Stroke Foundation, 2008). Men over the age of 55 years and postmenopausal women are at greater risk of heart disease. Thus, until women reach menopause they have a lower risk (Heart and Stroke Foundation, 2008). If one's close family members, such as parents, children, and siblings have had a stroke, one is at higher risk (Heart and Stroke Foundation, 2008). First Nations people and those of African or South Asian descent are more likely to have high blood pressure and diabetes, and therefore are at greater risk for stroke than the general population (Heart and Stroke Foundation, 2008). The weak areas in an artery wall or abnormal arteries and veins can increase an individual's risk for stroke (Goldstein et al., 2011).

Individuals can modify some of the risk factors for stroke, such as quitting smoking, controlling high cholesterol, stabilizing high blood pressure, managing diabetes, maintaining a healthy weight, limiting alcohol intake, avoiding cocaine and other illegal drug use, maintaining a healthy diet, and getting regular exercise (Messing, 2003; Solenski, 2004).

Diagnosis

According to the Heart and Stroke Foundation (2009), there are five warning signs of stroke: 1) Weakness: Sudden weakness, numbness or tingling in the face, arm or leg; 2) Trouble speaking: Sudden temporary loss of speech or trouble understanding speech; 3) Vision problems: Sudden loss of vision, particularly in one eye, or double vision; 4) Headache: Sudden severe and

unusual headache; and, 5) Dizziness: Sudden loss of balance, especially with any of the above signs. Stroke symptoms require immediate medical attention to reduce the risk of death and improve the chances of best recovery (Lezak, 2004; Pancioli et al., 1998). It is recommended that patients go directly to the hospital as soon as symptoms are noticed to enable treatment within the first 4.5 hours of stroke (Lindsay et al., 2010). Patients and families should be able to recognize and respond immediately to the warning signs of stroke by calling 9-1-1 or their local emergency number. People with strokes often arrive at the hospital in the hyper-acute phase, which necessitates the healthcare activities that take place between the time of first contact with a potential stroke patient, either upon admission to the hospital or during outpatient management in the community. A shorter time between the stroke event and arrival at the hospital can significantly affect survival and recovery. Fifty-four percent of patients who seek acute care for stroke arrive at the emergency department by ambulance, while a significant proportion of the remaining individuals will seek help from their primary care physician (Lindsay et al., 2010). If an individual or family member has symptoms that are potentially stroke-related, or have risk factors for stroke, their doctor may conduct a number of tests to help diagnose and treat stroke. The doctor will first determine if the individual has had a stroke, and if so, what type of stroke has been experienced. The doctor will further investigate with tests (Heart and Stroke Foundation, 2009).

A physical examination will likely be the first diagnostic test to determine what kind of stroke the person may have had. This exam could include (Aminoff, 2005): 1) observing how the person looks and acts. For example, it is important to evaluate if the person has any signs that are consistent with stroke, such as paralysis or weakness on one side, and trouble speaking or understanding speech; 2) listening to the person's heart to see if there are any sounds that might

indicate if the client has a heart rhythm disorder; 3) listening to the lungs and bowels for sounds that might indicate problems; 4) looking in the person's eyes for signs of hemorrhage (blood spots), high blood pressure or reduced blood flow (ischemia); 5) taking the client's blood pressure; 6) checking his/her reflexes; and, 7) asking the patient or a family member a series of questions, including: "What warning signs are you experiencing?"; "What medications is the patient taking?"; "If there's a family history of stroke or heart disease, what is the patient's past health and medical history?"; and "What are the patient's risk factors for stroke" (Aminoff, 2005).

Cerebral angiography (also known as arteriography) is a test that takes pictures of the blood flowing through the arteries in the patient's neck and brain. A dye that shows up on X-rays is injected into an artery and a series of rapid-image X-rays are taken as the dye travels through the arteries. These X-rays will show the doctor how blood is flowing and the size and location of any blockages. This procedure is also sometimes used to help identify problems or malformations in blood vessels, such as aneurysms or arteriovenous malformations (AVM) (Heart and Stroke Foundation, 2008).

Depending upon what the doctor is looking for, any of the following blood and urine tests may be used: how smoothly the blood flows through the vessels; testing the time it takes for the blood to clot and the level of a clotting component called fibrinogen; and testing the blood cholesterol levels, blood sugar (glucose) levels, and the blood calcium levels (Heart and Stroke Foundation, 2008).

A carotid ultrasound uses sound waves to examine blood flow in the patient's carotid arteries. These arteries are located on both sides of one's neck and carry blood to the brain. Sound waves are delivered through a transducer (a unit that directs the sound waves),

which is placed over the carotid artery. The sound waves are converted into an image on a monitor (Heart and Stroke Foundation, 2008). This kind of ultrasound can help the doctor to find any narrowing or blockage of the carotid arteries.

A CT or CAT scan is often one of the first tests scheduled for someone who has had a stroke. The CT scanner is a large device that takes a series of X-rays of the head. The images appear as a series of thin slices that show details of the brain's anatomy (Heart and Stroke Foundation, 2008). In some cases, a contrast dye may be injected to better define tissues and blood vessels on the scans and enhance the images.

An echocardiogram uses sound waves (ultrasound) to create a picture of the patient's heart. The recorded waves show the shape, texture and movement of the patient's heart valves, as well as the size of the heart chambers and how well they are working (Heart and Stroke Foundation, 2008). This procedure may be done to determine whether a stroke was caused by a heart condition and can also help to determine if there is a risk of blood clots forming in the patient's heart.

An electrocardiogram (ECG or EKG) is a test that checks how the patient's heart is functioning by measuring the electrical activity of the heart. With each heartbeat, an electrical impulse (or wave) travels through the heart. This wave causes muscles to squeeze and pump blood from the heart. By measuring how long the electrical wave takes to pass through the patient's heart, the cardiologist can determine if the electrical activity is normal, fast or irregular. By measuring the amount of electrical activity passing through the heart, the cardiologist may be able to determine if the patient's heart is enlarged or overworked (Heart and Stroke Foundation, 2008).

An electroencephalogram (EEG) is a test that investigates the electrical activity in the brain. It may be performed to check if any damage occurred in the patient's brain after a stroke. It is also commonly used to diagnose epilepsy (Heart and Stroke Foundation, 2008).

Holter monitoring is usually used to diagnose heart rhythm disturbances, specifically to find the cause of palpitations or dizziness. Patients wear a small recording device, called a Holter monitor, which is connected to small metal disks (called electrodes) that are placed on one's chest to get a reading of the heart rate and rhythm over a 24-hour period or longer. The heart's rhythm is transmitted and recorded on a tape, then played back into a computer so it can be analyzed to find out what is causing the arrhythmia (Heart and Stroke Foundation, 2008). Some monitors let a patient push a "record" button to capture a rhythm as soon as the patient feels any symptoms.

An MRI is a large imaging device that sits in its own room. It uses a harmless magnetic field and radio waves to get clear, sharp pictures of the inside of the patient's brain. An MRI is used to detect bleeding in the brain, tumours or stroke (Kumral, Bayulkem, Evyapan, & Yuntun, 2002). It is also an excellent device for detecting smaller strokes or strokes in the back of the brain, which other imaging devices can miss (Heart and Stroke Foundation, 2008). MRI images show even more detail than CT scans, and can be viewed in 3-D on a computer screen.

A neurological exam will provide the doctor with important information about how a patient's brain has been affected by a stroke.

A transesophageal echocardiogram (TEE) is a special type of echocardiogram. It is usually done when the doctor wants to look more closely at a patient's heart to see if it is producing blood clots. Like an echocardiogram, the TEE uses high-frequency sound waves (ultrasound) to examine the structures of the heart (Heart and Stroke Foundation, 2008). A

transducer (a unit that directs the sound waves) is placed in the esophagus (the pipe that connects the mouth to the stomach). The esophagus is close to the heart, so images from a TEE can give very clear pictures of the heart and its structures (Heart and Stroke Foundation, 2008).

These images can show the doctor whether a stroke was caused by a blood clot (ischemic stroke) or uncontrolled bleeding (hemorrhagic stroke). The images also help rule out other processes in the brain that can mimic the effects of a stroke. If the CT scan confirms that the stroke was caused by a blood clot within a 4.5 hour-window from symptom onset, a clot-busting drug known as tPA can be administered, which may reduce the effects of stroke (Lindsay et al., 2010).

Symptoms of Stroke

Stroke is also known as a clinical syndrome rather than a single disease (Frizzell, 2005). As the National Clinical Guidelines for Stroke developed by the Scottish Intercollegiate Guidelines Network (SIGN) (2008) pointed out, stroke is not a homogeneous grouping. With more than 100 potential causes, there may be as many different presentations for strokes as there are patients (SIGN, 2008). Although the pathophysiological mechanisms and resulting symptoms vary widely, stroke presentation and its impact on disability can be broadly grouped. Stroke presentation depends on the territory of the brain tissue affected. Brain functioning occurs in an integrated fashion (Pilkington, 1999). When damage occurs in one region of the brain, not only are those specialized centers associated with the impaired region affected, but also the entire brain suffers from loss of input from the injured part (Wlodek, Sandercock, & Czlonkowska, 2004). Medical complications can also follow as a result of stroke, which place a larger burden on the caregiving role. These conditions can include urinary incontinence (Wade & Hewer, 1987) and bowel control problems, pain, sleep apnea, seizures, pyrexia (fever), deep vein

thrombosis, pulmonary embolism (PE), dysphagia (problems swallowing), and malnutrition (Delaney, & Potter, 1993).

Physical Deficit. The most common presentation of a person with stroke requiring rehabilitation is paralysis. The paralysis is usually on one side of the body opposite the side of the brain damaged by stroke, and may affect the face, an arm, a leg, or the entire side of the body. This one-sided paralysis is called hemiplegia, and it involves complete inability to move or hemiparesis if it is less than total weakness (National Institute of Neurological Disorders and Stroke, 2008). Stroke patients with hemiparesis or hemiplegia may have difficulty with everyday activities such as walking or grasping objects. Some stroke patients have problems with swallowing, called dysphagia (Kwasnica, 2002). Dysphagia is due to damage to the part of the brain that controls the muscles for swallowing. Damage to a lower part of the brain, the cerebellum, can affect the body's ability to coordinate movement, a disability called ataxia, leading to problems with body posture, walking, and balance (Kwasnica, 2002). Other neurological manifestations will vary depending upon the side (of brain) of the stroke lesion and whether the stroke occurs in the cerebral hemispheres or the brainstem. Impairments associated with a stroke exhibit a wide diversity of clinical signs and symptoms. Disability is multifactorial in its determination. In other words, disability varies according to the degree of neurological recovery, the site of the lesion, the patient's previous health status, and the environmental support systems (National Stroke Foundation, 2005).

Cognitive Deficit. Aphasia is one of the common impairments following stroke and is characterized by difficulties in language and communication, including auditory comprehension and the formulation of grammatical verbal messages (e.g. verbal fluency and naming) (Mukherjee, Levin & Heller, 2006). Reading and writing difficulties may also occur

(Hochstenbach & Mulder, 1999). The communication problems include expressing and understanding verbal or non-verbal language cues (Hochstenbach & Mulder, 1999; National Stroke Foundation, 2005). Speech skills such as narrative organization and delivery can also be affected (National Stroke Foundation, 2005).

Speech and language problems are found to be more prominent in left-sided stroke, while visual perceptual deficits, including auditory and visual affect recognition (e.g. difficulties with understanding emotional and social cues such as gesture, tones and facial expressions), are more common with right-sided stroke lesions (Lezak, 2004; Mukherjee et al., 2006). Other visual recognition problems include unilateral neglect. Unilateral neglect affects either sensory or motor systems and is characterised by a failure to perceptually attend to or voluntarily move towards visual and auditory information from one side of the post-stroke person's environment. This sensory or auditory information appears contralateral to the lesion location (i.e. usually in the left field of vision or part of the body following right-sided lesions), even though sensory processing abilities and muscle tone and strength remain intact (Hochstenbach & Mulder, 1999). Disorders of object recognition (visual agnosia) and prosopagnosia (an inability to recognize familiar faces) can also arise with some types of lesions, again despite intact visual perception (Hochstenbach & Mulder, 1999). Agnosia does not only impair object, body part or facial recognition, but can also hinder other sensory modalities such as olfaction and hearing (e.g. recognizing the danger of smoke) (National Stroke Foundation, 2005).

Other cognitive deficits following stroke predominantly include difficulties with attention, memory (Madureira, Guerreiro & Ferro, 2001; Teasdale & Engberg, 2005) and executive (frontal lobe) functioning (Kumral, Bayulkem, Evyapan, & Yuntun, 2002; Mukherjee et al., 2006). Visual-spatial ability has also been found to decline; however, attention, memory and

executive functioning are more significantly affected (Knopman et al., 2009).

Selective, focused, divided and sustained attention can be compromised following stroke. This can inhibit a post stroke individual's ability to concentrate on tasks for a prolonged period, especially in the face of distractions or when needing to perform two tasks at the same time. Information processing speed can also be slowed, which leads one to think and act slowly. This can lead to social withdrawal and fatigue for a post-stroke individual (Hochstenbach & Mulder, 1999). Memory can also be impaired in relation to both the storage and retrieval of information. Memory dysfunctions may impair people's ability to recall or recognize episodic information, and can cause serious problems in the life of stroke individuals (Hochstenbach & Mulder, 1999). For example, post-stroke individuals may forget to take their medication. This forgetfulness can essentially affect their overall ability to learn skills and to function independently without a caregiver.

Executive functioning involves the integration of skills including the ability to control, organize, and monitor one's cognitive processes, emotions, and behaviours (Brookshire, Levin, Song, & Zhang, 2004; Kennedy et al., 2008). With stroke, executive functions cannot be applied to solving problems and/or conforming to socially appropriate norms of behaviour (Brookshire et al., 2004). Deficits in executive functioning include problems in organizing, planning, multitasking, poor problem solving, and emotion dysregulation (Cicrone & Tanenbaum, 1997; Kennedy et al., 2008; Lezak, 2004). Furthermore, executive dysfunctions can sometimes be misinterpreted by others as a lack of motivation (Hochstenbach & Mulder, 1999). Executive dysfunction can also leave a stroke survivor seriously dependent on others for external structures or supports, and routines (Hochstenbach & Mulder, 1999). Dementia and mild cognitive impairment (MCI) have also been associated with stroke (Knopman et al., 2009; Madureira et al.,

2001).

Any one of the above deficits can serve to inhibit the post-stroke individual's ability to function independently, affecting everyday activities such as reading, writing, walking, and staying safe in various situations such as in traffic (National Stroke Foundation, 2005). One of the key roles of family or friend caregivers of stroke survivors is to help manage these deficits which can be stressful and time consuming for all concerned.

Neuropsychosocial Deficit. Besides physical and cognitive consequences described above, emotional wellbeing and neuropsychosocial outcomes can also arise (Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 2000) which affect the post stroke individual's recovery and their caregiver's well-being. Researchers suggested the need to include comprehensive neuropsychological tests in the assessment of those who have suffered vascular accidents. There is also evidence that neuropsychological factors are more important determinants of functional outcomes after stroke than physical disability (Bays, 2001; Hochstenbach, Anderson, van Limbeek, & Mulder, 2001; Kotila, Numminen, Waltimo, & Kaste, 1999; Labi, Phillips & Greshman, 1980; Lynch, Kaplan, & Shema, 1997; Morris, Robinson, Andrzejewski, Samuels, & Price, 1993; Paolucci, Antonucci, Gialloreti, Traballes, Lubich, 1996; Zhu, Fratiglioni, Guo, Guero-Torres, Winblad, 1998), and can account for a large proportion of the variance in strain experienced by caregivers of individuals with stroke (Zak, 2000).

Emotional changes following a stroke have been well documented (Dennis et al., 1998). The most widely researched and commonly found emotional difficulties are depressive symptoms (e.g. Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 1998; Hackett, Yapa, Parag & Anderson, 2005; Mackenzie et al., 2007; Young, Murray & Forster, 2003). Correctly assessing depression in stroke individuals is difficult due to the nature of stroke symptoms that can be

confused with depression (Berg, Lonnqvist, Palomaki & Kaste, 2008). For post stroke individuals, the symptoms of depression can be confounded by other neurological and cognitive stroke symptoms (Hackett, Anderson, House & Xia, 2008), which may lead to over- or under-diagnosis of depression. For example, deficits in emotional expression due to brain injury as a result of stroke may be misinterpreted as depression (Hackett, Anderson, House & Xia, 2008). Despite this, some research provided evidence that as many as one third of individuals dealing with strokes experience significant depressive symptoms (Fuentes, Ortiz, SanJose, Frank, & Diez-Tejedor 2009; Hackett, Yapa, Parag & Anderson, 2005; Young et al., 2003). Furthermore, researchers suggested that these depressive symptoms are quite prevalent during all stages of recovery, with approximately 33% of stroke individuals exhibiting depressive symptoms in all phases of the stroke recovery process (Hackett et al., 2005; Kotila, Numminen, Waltimo & Kaste, 1998; Teasdale & Engberg, 2005).

Depression in stroke survivors can either be a primary response from the amount of direct brain tissue damage and associated neural changes, or a secondary response that results from a reaction of the stroke individuals (and others) toward stroke symptoms and consequences (Hochstenbach & Mulder, 1999). Researchers have shown that the causes for depression following stroke are multifactorial and possess both biological, and psychological environmental attributes (Whyte & Mulsant, 2002). Specifically, post stroke individuals often report feelings of grief and loss in association with changes in their own independent functioning, reporting a difficulty with accepting and adapting to life because they are no longer able to carry out activities or roles they previously could (Clarke & Black, 2005). Furthermore, changes in physical functioning can reduce the degree of social interaction and lead to social isolation, loneliness, and depression (Haun, Rittman & Sberna, 2008; Young, Bogle, & Forster, 2001).

Anxiety and related emotional responses, such as insecurity and distrust can also occur following stroke, and are often associated with depression (Hochstenbach & Mulder, 1999; Mineka, Watson & Clark, 1998). Anxiety is generally associated with a perceived, future oriented threat that may or may not be realistic. Whether the perceived threat is realistic or not, anxiety can cause severe distress and impairment in everyday life, such as in concentration and participation in activities (American Psychiatric Association, 2000; Wells, 2005). Stroke survivors have reported various anxious thoughts related to the consequences of stroke such as a fear that another stroke will occur (Clarke, 2009), concern about the welfare of their caregiver (if applicable), apprehension around engaging in physical activities, negative evaluation from peers, interpersonal problems, and a loss of control in their behaviour (National Stroke Foundation, 2007).

Other emotional problems can include outbursts of anger and irritability (Mukherjee et al., 2006; Teasdale & Engberg, 2005) or feelings of resentment towards other people or for the stroke occurring (Clarke & Black, 2005; Hochstenbach & Mulder, 1999). For example, stroke individuals may experience guilt or resentment towards their caregivers for assisting them (National Stroke Foundation, 2007). Finally, changes in personality and behaviour can also occur, which are sometimes related to cognitive impairments discussed above (particularly to executive dysfunction due to frontal lobe damage). The stroke survivor can become more self-centered, agitated, and impatient in relation to change or unpredictability. Compulsive and inappropriate crying or laughing or, in contrast, emotional bluntness and indifference can also occur (Hochstenbach & Mulder, 1999). Some researchers have argued that emotional reactivity has been associated with left-sided stroke whilst restricted affect expression is more likely to arise following right-sided stroke (Hochstenbach & Mulder, 1999; Lezak, 2004). However, these

claims on stroke lesion location are debatable, and authors of an extensive systematic review of depression after stroke found no support for the claim that depression is influenced by the brain region in which the stroke damage occurred (Carson et al., 2000).

Understanding the effect of emotional and behavioural problems is required to inform health care providers on how to tailor effective rehabilitation programs (Visser-Meily, Rhebergen, Rinkel, van Zandvoort, & Post, 2009) and how to appropriately educate caregivers. The education of caregivers about stroke includes acknowledging the consequences of stroke to assist post stroke individuals and their caregivers in establishing realistic and shared goals in the process of recovery.

In summary, the types and degrees of disability that follow a stroke depend upon which area of the brain is damaged and how much is damaged. It is difficult to compare one individual's disability to another's, since every stroke can damage slightly different parts and amounts of the brain. Generally, stroke can cause five types of disabilities: paralysis or problems controlling movement, sensory disturbances including pain, problems using or understanding language, problems with thinking and memory, and emotional disturbances.

Functional Assessment Tools

Commonly used measurements to assess physical functioning, including activities of daily living (ADLs) are the Barthel Index, Modified Rankin Scale, the Short Form-36, and the Stroke Impact Scale (Hobart, Williams, Moran, & Thompson, 2002). The following describes each of these assessment tools that evaluate the patient's physical functioning.

Barthel Index. The Barthel Index consists of 10 items that measure a person's daily functioning, specifically ADLs and mobility. It was modified by Granger et al. in 1979 and includes a 0 to 10 point rating scale for every item in the tool. Further refinements were

introduced in 1989 (Shah, Vanclay, & Cooper, 1989). The tool's items include: feeding, transferring from wheelchair to bed and return, grooming, transferring to and from a toilet, bathing, walking on a level surface, going up and down stairs, dressing, and continence of bowels and bladder (Mahoney & Barthel, 1965). The tool can be used to determine a baseline level of functioning and to monitor improvement in activities of daily living over time. The person receives a score based on whether they have received help while doing the task (van der Putten, Hobart, Freeman, & Thompson, 1999). The scores for each of the items are summed to create a total score. The higher the score, the more "independent" the person is. Independence means that the person needs no assistance with any part of the task. If a person is able to perform 50% of the task independently, then the "middle" score would apply (Mahoney & Barthel, 1965). The scale is regarded as reliable, although its use in clinical trials in stroke medicine is inconsistent (Sulter, Steen, & De Keyser, 1999). However, it has been used extensively to monitor functional changes in individuals receiving in-patient rehabilitation, mainly in predicting the functional outcomes related to stroke (Sulter, Steen, & De Keyser, 1999). The Barthel index has demonstrated high reliability (0.95) and test re-test reliability (0.89) as well as high correlations (0.74-0.80) with other measures of physical disability (Carroll, 2011).

Modified Rankin Scale. The modified Rankin Scale (mRS) is a commonly used scale for measuring the degree of disability or dependence in ADLs people who have suffered from stroke (Farrell, Godwin, Richards, & Warlow et al., 1991). It has become the most widely used clinical outcome measure for stroke clinical trials. It was originally introduced by Rankin (1957), and modified to its current form by Professor Warlow's group at Western General Hospital in Edinburgh, and was used in the UK-TIA study in the late 1980s (Farrell, Godwin, Richards, &

Warlow et al., 1991). The first publication of the current modified Rankin Scale was in 1988 by van Swieten, Koudstaal, Visser, Schouten et al. (Farrell, Godwin, Richards, & Warlow et al., 1991). The scale is employed by clinicians mainly to evaluate patients' functional outcome after stroke. The tool is based on a 0 to 6 rating scale: 0 indicates perfect health and 6 indicates death (van Swieten, Koudstaal, Visser, Schouten et al., 1988). Although individual raters are consistent in their use of the mRS, inter-rater variability is substantial and problematic for studies involving multiple raters (van Swieten et al., 1988). There is no evidence that improvement in inter-rater agreement can occur simply with repetition in using the tool. Use of a structured interview improves agreement among raters in the assessment of global outcome after stroke (van Swieten et al., 1988).

Short Form 36: The SF-36 is a multi-purpose, short-form health survey with 36 questions (Ware, Kosinski, & Keller, 1994). It yields an 8-point rating scale for the following items: physical functioning (PF), vitality (VT), role physical (RP), social functioning (SF), bodily pain (BP), role emotional (RE), general health perceptions (GH), mental health (MH) profile of functional health, and well-being scores, as well as psychometrically-based physical and mental health summary measures, and a preference-based health utility index (Ware et al., 1994). The SF-36 is used to monitor specific and general populations to estimate disease burden (Ware et al., 1994). After distribution, the SF-36 can be used to quantify the severity of an individual's post development health issues at any point in time, as well as allow for comparisons of an individual's health status over time (Ware et al., 1994).

In 1996, Version 2.0 of the SF-36 (SF-36v2) was introduced to correct deficiencies identified in the original version (Ware, Kosinski, & Dewey, 2000). The SF-36 (v. 2) Health Survey asks 36 questions to measure functional health and well being from the patient's point of

view (Ware et al., 2000). It is a practical, reliable, and valid measure of physical and mental health that can be completed in five to ten minutes (Ware et al., 2000). Published reliability statistics have exceeded the minimum standard of 0.70 recommended for measures used in group comparisons in more than 25 studies (Tsai, Bayliss, & Ware, 1997); most have exceeded 0.80. Reliability estimates for physical and mental summary scores usually exceed 0.90 (Ware, Kosinski, & Keller, 1994). A review of the first 15 published studies revealed that the median reliability coefficients for each of the eight scales was equal to or greater than 0.80 except for SF, which had a median reliability of 0.76 across studies (Ware, Snow, Kosinski, & Gandek, 1993). In addition, a reliability of 0.93 has been reported for the Mental Health scale using the alternate forms method, suggesting that the internal-consistency method underestimated the reliability of that scale by about three percent (McHorney & Ware, 1995).

Stroke Impact Scale. The Stroke Impact Scale (SIS) has been developed which assesses other dimensions of health related quality of life, including: emotion, communication, memory and thinking, and social role function (Duncan et al., 1999). The Stroke Impact Scale was developed at the University of Kansas Medical Center and was based on feedback from patients and their caregivers (Duncan et al., 1999). The SIS measures aspects of stroke recovery which were found to be important to patients and caregivers, as well as stroke experts (Duncan et al., 1999). After intensive psychometric testing, a 59- item Stroke Impact Scale Version 3.0 was developed (Duncan, Lai, Tyler, Perera, Reker, & Studenski, 2002). The 59 questions of the SIS version 3.0 are broken down into eight domains: strength, hand function, mobility, activities of daily living, emotion, memory, communication, and social participation (Duncan et al., 2002). The SIS version 3.0 is available in a proxy version when patients are unable to complete the tool (Duncan et al., 2002).

In summary, stroke often results in psychological distress and activity limitations across multiple domains of functioning. Some stroke outcomes may have independent prognostic implications (Doyle, 2002). For this study, it was important for the researcher to consider using a patient-centered tool that can capture caregivers' perceptions of the multiple dimensions of patient functioning, that in turn can influence emotional and behavioural responses of family caregivers and patients when dealing with stroke outcomes.

Best Practice Guidelines for Treatment

The Canadian Best Practice Recommendations for Stroke Care (Lindsay et al., 2010) was funded by the Canadian Stroke Strategy, and was a joint initiative of the Canadian Stroke Network and the Heart and Stroke Foundation of Canada. The Canadian Best Practice Recommendations for Stroke Care (Lindsay et al., 2010) presents high-quality, evidence-based stroke care recommendations in a standardized framework to support healthcare professionals in all disciplines. Implementation of these recommendations is expected to contribute toward reducing practice variations and close the gap between evidence and practice (Hodwitz & Bayley, 2011; Lindsay et al., 2010).

With ischemia stroke, two timelines have been established to provide emergency medical services in Canada within the 4.5 hour-window from symptom onset to administration of thrombolytic therapy, which are: a) The pre-hospital phase that starts with symptom onset and includes on-scene management and transport time, which should be 3.5 hours or less; b) The emergency department phase that includes the diagnostic evaluation and receiving treatments, which should be less than 60 minutes (Lindsay et al., 2010). This time frame is vital for the patient to receive the thrombolytic therapy (Lindsay et al., 2010). Therefore, patients should use the 9-1-1 Emergency Medical Service systems for transport to the nearest hospital where

physicians can determine the need to administer a tissue plasminogen activator (t-PA) (Smith, Johnston & Easton, 2005). Carotid endarterectomy is an early secondary prevention surgery that helps to remove plaque along the walls of the carotid arteries which are major blood vessels in the neck that supply blood to the brain (Barnett, Taylor, & Eliasziw et al., 1998). Treatments that decrease the occurrence of blood clots such as antiplatelet (e.g. aspirin) and anticoagulation medications can also help to reduce further tissue damage, and lower the risk of future strokes in the long-term maintenance period of stroke recovery (Lindsay et al., 2010). Risk factor management, such as medication that lowers blood pressure, is also commonly prescribed for stroke individuals (Lindsay et al., 2010).

Most cerebral hemorrhages develop rapidly over 30 to 90 minutes, often with rapid loss of consciousness (Solenski, 2004). Therefore, it is crucial to maintain a patent airway (Solenski, 2004). Initial treatment includes intubation, hyperventilation, elevation of the head of the bed, and administration of intravenous mannitol to prevent and reduce elevated intracranial pressure (Solenski, 2004).

After the hyperacute phase, most of the patients will be admitted to the stroke unit for further stabilization of the symptoms, and to prevent complications. The core interprofessional team on the stroke unit should consist of healthcare professionals with stroke expertise from medicine, nursing, occupational therapy, physiotherapy, speech-language pathology, social work, and clinical dietetics (Lindsay et al., 2010). Additional disciplines may include pharmacy, (neuro) psychology, and recreation therapy (Lindsay et al., 2010). The interprofessional team should assess patients within 48 hours of admission to hospital and formulate a management plan (Lindsay et al., 2010). Clinicians should use standardized, valid assessment tools to evaluate the patient's stroke-related impairments and functional status (Lindsay et al., 2010).

The team will assist the patient to manage the risk factors of stroke or other cardiovascular disease, and start an initial rehabilitation program (Lindsay et al., 2010). The rehabilitation plays a significant role in the patient's recovery. At the same time, a patient's recovery is closely related to functional deficits from the stroke event (Lindsay et al., 2010).

Stroke Rehabilitation

The Canadian Best Practice Recommendations for Stroke Care (2010) provided evidence-based recommendations for stroke rehabilitation (Lindsay et al., 2010). Rehabilitation includes both outpatient and inpatient care (Lindsay et al., 2010). Outpatient rehabilitation includes day hospital, outpatient ambulatory care, and home-based rehabilitation (Teasell, Foley, Bhogal, Chakraverty, & Bluvol, 2005). Inpatient care occurs on rehabilitation units (Lindsay et al., 2010). All persons with acute stroke should be assessed to determine the severity of the stroke and early rehabilitation needs (Lindsay et al., 2010). All patients admitted to hospital with acute stroke should have an initial assessment by rehabilitation professionals as soon as possible after admission, preferably within the first 24 to 48 hours (Lindsay et al., 2010). This initial assessment should include assessments of patient functional status, safety and risk, physical readiness, ability to learn and participate, and transition planning (Lindsay et al., 2010). All patients with acute stroke with any residual stroke-related impairment who are not admitted to hospital should undergo a comprehensive outpatient assessment for functional impairment, which includes a cognitive evaluation, screening for depression, screening for fitness to drive, as well as functional assessments for potential rehabilitation treatment, preferably within two weeks (Lindsay et al., 2010). Clinicians should use standardized, valid assessment tools to evaluate the patient's stroke-related impairments and functional status (Lindsay et al., 2010). The rehabilitation needs of survivors of a severe or moderate stroke should be reassessed weekly for

the first month, and then at intervals as indicated by their health status (Lindsay et al., 2010). All patients with stroke who are admitted to hospital and who require rehabilitation should be treated in a comprehensive or rehabilitation stroke unit by an interprofessional team (Lindsay et al., 2010).

Post-acute stroke care should be delivered in a setting in which rehabilitation care is formally coordinated and organized. All patients should be referred to a specialist rehabilitation team as soon as possible after admission (Lindsay et al., 2010). The interprofessional rehabilitation team should consist of a physician, nurse, physical therapist, occupational therapist, speech-language pathologist, psychologist, recreation therapist, patient, social worker and family and/or caregivers (Lindsay et al., 2010). Final discharge evaluation is measured with standard tools by all disciplines, in order to decide the discharge location, such as the patient's home or a personal care home (Lindsay et al, 2010).

All patients with stroke should begin rehabilitation therapy within an active and complex stimulating environment as early as possible once medical stability is reached (Lindsay et al., 2010). Patients should receive clinically relevant therapy as defined in their individualized rehabilitation plan that is appropriate to their needs and tolerance levels (Lindsay et al, 2010). Stroke patients should receive, through an individualized treatment plan, a minimum of three hours of direct task-specific therapy by the interprofessional stroke team for a minimum of five days per week (Lindsay et al., 2010). The team should promote the incorporation of the practice of skills gained in therapy into the patient's daily routine in a consistent manner (Lindsay et al., 2010). Therapy should include repetitive and intense use of different tasks that challenge the patient to acquire necessary motor skills to use the involved limb during functional tasks and activities (Lindsay et al., 2010). Stroke unit teams should conduct at least one formal

interprofessional meeting per week at which patient problems are identified, rehabilitation goals are set, progress is monitored and support after discharge is planned (Lindsay et al., 2010). The care management plan should include a pre-discharge needs assessment to ensure a smooth transition from rehabilitation back to the community (Lindsay et al., 2010). Elements of discharge planning should include a home visit by a healthcare professional, ideally before discharge, to assess the home environment and its suitability for safe discharge, determine the need for equipment and/or home modifications, and begin caregiver training for how the family caregiver and the patient will manage activities of daily living and instrumental activities of daily living in their environment (Lindsay et al., 2010).

In summary, best practice recommendations are intended to guide health care providers in their interventions in post stroke care for patients and family caregivers. There are three phases representing recommended patient movement through the health care system, including patient care in an inpatient medical unit, an inpatient stroke rehabilitation unit, and then in an outpatient or community rehabilitation setting. Caregivers play a significant role during the rehabilitation process. Therefore, further research is warranted that focuses on developing evidence-based recommendations for family caregivers that support them in their care of the post-stroke individual.

Caregiving Experiences

Stroke individuals experience significant functional limitations resulting from decreased mobility, cognitive impairment, depression, and personality changes. The functional changes of stroke that have an impact on affected individuals also extend to family caregivers. Unlike caregivers of people with other chronic illnesses, there is usually no period of transition in stroke care. Stroke is a sudden event. Families or friends caring for individuals affected by stroke enter

their new role abruptly, often without the opportunity to adjust to the change and learn new skills (Draper & Brocklehurst, 2007). Therefore, caregivers may experience anxiety about prognosis and uncertainty about the future, as well as depression and other types of emotional distress (Brereton & Nolan, 2000; Greenwood, Mackenzie, Wilson, & Cloud, 2009; Gillespie & Campbell, 2011). Regardless of these negative emotions, family caregivers play a pivotal role in the stroke individual's recovery process and also in maintaining safe care of stroke survivors in the community (Anderson et al., 1995). Therefore, researchers have drawn attention to conducting both qualitative and quantitative studies to systematically capture the caregiving experience in stroke care. Most quantitative studies have focused on the negative experiences of caregivers of stroke survivors as described in the next section below. Conversely, qualitative researchers have described positive aspects of the lived experience of caregivers and the caregiving process during the post stroke time frame as explored in the subsequent section.

Caregiver Experiences Captured in Quantitative Studies

The quantitative literature has reported stroke caregivers' physical and psychosocial well-being in the caregiving process. Table 2.1 presents a summary of findings of studies that investigated caregivers' experiences in the caregiving process during the post stroke time frame.

Physical Wellbeing. To date, there exists very little research on the impact of providing care to people with stroke on their caregivers' physical health (Han & Haley, 1999). This is important information, especially since the majority of caregivers are elderly partners of stroke survivors (Kerr, 2001; Smith et al., 2004; Suh et al., 2005) who are likely dealing with their own chronic health conditions (Chow, Wong, & Poon, 2007; Lyons, Zarit, Sayer, & Whitlatch, 2002; Schulz, Tompkins, & Rau, 1988). Caregiving can place a physical burden on stroke caregivers (Kerr & Smith, 2001; White, Poissant, Cote-LeBlanc, Wood-Dauphinee, 2006) as they undertake

instrumental activities (e.g., home maintenance) that were often previously carried out by the stroke survivor.

The findings so far have been inconsistent: the extent to which stroke caregiving leads to new medical problems or exacerbates pre-existing conditions in caregivers prior to the stroke is uncertain. On the one hand, stroke caregivers with chronic medical problems can experience deterioration in their own physical health after becoming a caregiver (Chow et al., 2007). Other researchers described physical deterioration in caregivers over the course of one year after the stroke of a family member (Scolte, Richter, Frank, & Wallesch, 2006; Simon, Kumar, & Kendrick, 2009). One to two years post-stroke, caregivers have reported their own experiences of having a lack of energy and vitality, sleep problems, headaches, and fatigue (Anderson et al., 1995; Kerr & Smith, 2001; Smith et al., 2004; White, Mayo, Hanley, & Wood-dauphinee, 2003). It is not clear how these conditions are associated with depression. According to one longitudinal study, increasing age and depression may predict their physical health status (Chow et al., 2007). Poor physical health has been related to increased rates of long-term depressive symptoms (Schulz et al., 1988). Conversely, other researchers have found few or no detrimental changes to physical health in association with the caregiver role (Chow et al., 2007; Parag, Hackett, & Yapa et al., 2008; Simon et al., 2009; Smith et al., 2004).

Caregiver Psychological Wellbeing. Caregivers reported lower mental health when caring for stroke individuals with a combination of lost memory and behavioural changes that were associated with caregiver stress (Clark, Dunbar, & Shields, 2004; Forsberg-Warleby, Moller, & Blomstrand, 2004; Singh & Cameron, 2005; Stone et al., 2004), and anxiety (Wilz & Kalytta, 2008). In order to cope with the emotional distress, the caregiver's appraisal of the stroke individual's consequences and capacity to cope were more important than the objective

degree of disability (Forsberg-Warleby, Moller, & Blomstrand, 2001; van den Heuvel, de Witte, Schure, Sanderman, Meyboom-de Jong, 2001). As with people who experienced stroke, symptoms of depression, anxiety and other emotional problems were common in caregivers of stroke survivors, and were the most frequently studied of all emotional states (Han & Haley, 1999). Depressive symptoms also functioned as key indices of caregiver burden, distress, and strain. The prevalence of caregiver depressive symptoms was found to range from between 39-55% across various studies (Anderson et al., 1995; Berg, Palomaki, Lonnqvist, Lehtihalmes, & Kaste, 2005; Cameronm Cheung, Striner, Coyte, & Stewart, 2006; Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 1998; Han & Haley, 1999; Kotila, Numminen, Waltimo, & Kaste, 1998; Morimoto, Schreiner, & Asano, 2003). Caregivers of stroke individuals experienced depressive symptoms during both the acute and chronic phases of stroke recovery (Han & Haley, 1999). Depressive symptoms were not only found to remain over the long-term but could also increase from one to three years after stroke (Visser-Meily et al., 2009). Furthermore, these depressive symptoms could inadvertently influence the stroke survivor and recovery process (Franzen-Dahlin et al., 2006; Mackenzie et al., 2007; Suh et al., 2005). There were several factors associated with caregiver depression. Caregiver depression was associated with stroke severity or dependency (Berg et al., 2005; Grant, Weaver, Elliott, Bartolucci, & Giger, 2004; Peyrovi, Mohammad-Saeid, Farahani-Nia, Hoseini, 2012; Smith et al., 2004). According to other literature, caregivers' negative appraisal (King et al., 2001), passive coping strategies (Visser-Meily et al., 2005), and perceptions of low control over the situation (Molloy et al., 2005) were risk factors or predictors of caregiver depression. However, caregivers who perceived they had high mastery over the caregiving situation had significantly fewer depressive symptoms than caregivers with low mastery (Kruithof, Visser-Meily, & Post, 2012; Schreiner & Morimoto,

2003). Other investigators demonstrated the benefits of caring for someone with stroke (Johnson, 1998). Experiencing positive outcomes and enjoyment from the process of caregiving can be influenced by the individual's appraisal of the caregiving situation as well as the amount of objective burden (Hilgeman, Allen, DeCoster & Burgio, 2007).

Two thirds of reviewed studies were cross-sectional while the remaining studies examined caregiver experiences over time. However, the timing of the assessment varied: e.g., measurement of caregiver experiences since 'the time of stroke' or 'the time since discharge'. The frequency of measurement was either unclear or not mentioned in study reports. However, the most common time of assessment was at six months to one-year post stroke. In addition, most of the studies used a negative emotion tool such as a depression scale (e.g., Beck Depression Inventory). The common use of negative emotion tools might contribute to the findings of predominantly negative emotions being experienced by family caregivers. However, there are general assessment tools that can measure both positive and negative aspects of the caregiving experiences (e.g., Short Form 36). Importantly, some researchers who employed tools that incorporated both positive and negative emotions found that high mastery caregivers had a significantly reduced burden when caring for individuals with stroke (Schreiner & Morimoto, 2003; Singh & Cameron, 2005).

In summary, most of the articles reviewed captured negative emotions of caregivers of individuals with stroke. However, some studies captured positive emotions. Of the studies that captured positive emotions by family caregivers, hope was significant to family caregivers along the caregiving journey. Overall, across the caregiving journey, both positive and negative emotions were expressed by caregivers while caring for individuals dealing with post-stroke.

Therefore, a measurement tool that can capture both negative and positive emotions in family caregivers who care for individuals with post-stroke was warranted in this thesis study.

Table 2.1. Quantitative Researches on Caregiver Emotions

Authors (date) Country	Study Design / Aim	Sample (n) caregivers and age (years)	Stroke individual Age (years)	Caregiver outcomes	Key findings
Bakas & Burgener (2002) USA	Cross-sectional Aim to investigate predictors of emotional distress, general health, and caregiving outcomes in family caregivers of stroke survivors.	N=104 Mean age=62.15	Mean age=70.79	Emotional distress (POMS) Caregiver health (SF- 36 GH) Stroke-related caregiving outcomes (BCOS)	Caregiver low self-esteem, and high threat appraisal related to emotional distress.
Bakas et al. (2004) USA	Cross-sectional Aim to (a) identify which tasks were perceived as most time-consuming and difficult, (b) determine which of these tasks were most predictive of mood and other negative caregiver	N=116 Mean age=60.5	Mean age=70.5	Negative mood (POMS), negative caregiver outcomes (BCOS)	Difficulty in managing finances, and providing emotional support.

	outcomes, and (c) evaluate the psychometric properties of the Oberst Caregiving Burden Scale (OCBS) as a measure of tasks in stroke caregivers.				
Berg et al. (2005) Finland	Longitudinal Aim to assess the prevalence of depressive symptoms among caregivers of stroke survivors and to determine which patient- or stroke-related factors are associated with and can be used to predict caregiver depression during an 18-month follow-up after stroke.	N=98 Mean age=?	Mean age=55.3	Depression (BDI)	Exhaustion is related to caregivers' depression.
Blake & Lincoln (2000) UK	Cross-sectional Aim to identify the factors associated with carer strain	#1 Questionnaire N=222 Mean age=71 #2 Questionnaire	Mean age=?	Caregiver strain (CSI)	Stroke individual's negative affect was associated with caregiver

	following stroke	N=96 Mean age=69			strain.
Blake et al. (2003) UK	Longitudinal Aim to test the ability of a previously generated logistic regression model to predict caregiver strain from carer mood, negative affect and perceived patient functional ability.	Mean age=66.35	Mean age=68.63	Caregiver strain (CSI)	Caregiver mood, negative affect and caregiver perceived functional disability of stroke individuals were useful in predicting caregiver strain at 6 months.
Bluvol & Ford-Gilboe (2004) Canada	Cross-sectional Aim to examine the relationships among hope, family health promotion, and quality of life after stroke, by testing hypotheses derived from the Developmental Model of Health and Nursing.	N=40 Mean age=66.2	Mean age=69.5	Quality of life (QoL) (RNLI) Herth Hope Index (measure of hope), Health Options Scale (measure of health work), Reintegration to Normal Living Index (measure of quality of life)	There was a positive relationship between hope and QoL amongst spouses.

Cameron et al. (2006) Canada	<p>Cross-sectional</p> <p>Aim to determine the impact of stroke survivors' behavioural and psychological symptoms (BPS) on informal caregivers' experience of depression in the context of the caregiving situation.</p>	<p>N=94</p> <p>Mean age=60.8</p>	<p>Mean age=67.7</p>	<p>Depression (The Center for Epidemiological Studies Depression Scale)</p> <p>Caregiving Impact Scale</p> <p>Mastery Scale</p>	<p>There was a positive relationship between stroke survivors' behavioural and psychological symptoms, and caregivers' experiences of depression.</p>
Chumber et al. (2004) USA	<p>Cross-sectional</p> <p>Aim to examine the associations between Social Coherence, perceived burden (caregiver's perception of the effect of caregiving-related stress) and depressive symptoms of informal</p>	<p>N=102</p> <p>Mean age=59.9</p>	<p>Mean age=66.5</p>	<p>Depression Geriatric Depression Scale (GDS)</p> <p>Burden Sense of Competence Questionnaire</p>	<p>Greater caregiver satisfaction is associated with less caregiver depression and lower caregiver burden.</p>

	caregivers (family members and involved friends) of stroke survivors one month after the stroke.				
Clark et al. (2004) USA	Cross sectional Aim to examine the influence of stroke survivors' motor function, their memory and behaviour changes, and the family conflict surrounding stroke recovery on the mental and physical health of caregivers during the subacute recovery period.	N=132 Mean age=56.68	Mean age=62.21	Mental health Physical health (SF-36)	Caregiver physical health was not associated with family functioning or stroke survivor memory and behaviour changes.
Choi-Kwon et al. (2005) Korea	Cross-sectional Aim to illuminate the factors related to the caregiver burden in stroke survivors in Seoul, Korea	N=147 Mean age=55	Mean age=61.9	Sense of Competence Questionnaire	Caregiver anxiety was closely related to caregiver burden

Draper & Brocklehurst, (2007) UK	Cross-sectional Aim to investigate the impact of stroke on the patient's spouse, paying particular attention to psychiatric morbidity and the strain of caring, and correlating these with the degree of disability of the patient.	N= 44 couples Mean age=65	Mean age=67	Caregiver morbidity (General Health Questionnaire) Caregiver stress & Strain (Caregiver Strain Index)	Psychiatric morbidity and strain in the spouses were not directly proportional to the extent of the patient's disability. Spouses whose partners' speech were affected by the stroke were more likely to experience strain than those who were not.
Forsberg-Warleby et al. (2001) Sweden	Cross-sectional Aim to study the well-being of the spouses of stroke patients during the acute state of stroke and to identify factors that may influence their well-being.	N=83 Mean age=57	Mean age=58	Psychological well-being, life satisfaction (PGWB)	In the acute phase, caregiver psychological well-being was more affected by stroke severity than the level of disability.

Forsberg-Warleby et al. (2004) Sweden	<p>Longitudinal study</p> <p>Aim to investigate whether spouses' life satisfaction changed between their life prior to their partner's stroke, and at 4 months and 1 year after stroke, and to study the association between spouses' life satisfaction and objective characteristics of the stroke patients.</p>	<p>N=67</p> <p>Mean age=57</p>	Mean age=58	<p>Psychological well-being (PGWB)</p> <p>Life satisfaction (LiSat-9)</p>	<p>In the acute phase, caregiver psychological well-being (PWB) was related to the stroke individual's motor impairment. At 4 months post-stroke, caregiver PWB was related to stroke individual's cognitive impairment and self-care ability. At 1 year post-stroke, PWB was related to the stroke individual's motor and cognitive impairments.</p>
Grant et al. (2004) USA	<p>Longitudinal</p> <p>Aim to examine sociodemographic, physical and psychosocial characteristics of</p>	<p>N=52</p> <p>Mean age=56</p>	Mean age=74	Depression (CES-D)	<p>Caucasians had a higher risk of depression compared to African Americans.</p>

	family caregivers of stroke survivors at risk for depression				Family caregivers who are isolated from others may benefit from therapeutic interventions that facilitate social interaction and decrease caregiver burden.
Green & King (2010) Canada	Longitudinal Aim to examine the recovery trajectory for male patients and their wife-caregivers during the 12 months post discharge.	N=38 couple Caregiver mean age=58.5	Mean age=63.4	Depression (Beck Depression Index) Strain (Bakas caregiving outcomes Scale) Family function (Family Assessment Device)	During 12 months of post discharge, caregivers' psychosocial outcomes were not necessarily related to physical sequelae of mild stroke, and may be related to adjustments made to compensate for changes to marital structure and function.

Haley et al., (2009) USA	Cross-sectional Aim to determine the prevalence and stressfulness of stroke-related problems, and perceived benefits of caregiving, as reported by an epidemiologically-derived sample of caregivers of stroke survivors.	N=75 Mean age= 63.69	Mean age=?	Stressfulness of rating instrument (author developed) Positive Aspects of Caregiving Scale Center for Epidemiological Studies-Depression scale	Caregivers reported many benefits from caregiving, and some reported that caregiving enabled them to appreciate life more.
Jones et al. (2000) UK	Longitudinal Aim to assess patient mood and carer stress for stroke patients in the community following early hospital discharge.	N=82(caregivers) Mean age=?	N=125 (stroke patients) Mean age=71.6	Stress (RSS)	Caregiver stress was related to the severity of stroke-related disability.

King et al. (2001) USA	Longitudinal Aim (a) to examine changes in depression, physical health, and contextual and coping factors from hospitalization of the stroke survivor through the first 6–10 weeks of home care; and (b) to identify predictors of depression.	N=136 Mean age=57.5	Mean age=60	Depression (CED-D)	Depression was greater with lower health rating and more frequent use of cautious coping. Being female and negative appraisal was related to caregiver depression.
McCullagh et al. (2005) England	Longitudinal Aim to identify determinants of caregiver burden will help to target caregiver interventions.	N=232 Mean age=65.7	Mean age=74.	Caregiver burden QoL (CBS) QoL (EQ-VAS) & (EQ-5D)	Caregiver burden was determined by stroke patients' and caregivers' anxiety. Caregiver anxiety decreased over time. After 1 year post-stroke, caregiver depression and lack of support caused additional caregiver burden.

Morimoto et al. (2003) Japan	Cross-sectional 1. Aim to examine the relationship between caregiver burden and health-related quality of life in family caregivers of older stroke patients in Japan. 2. Aim to examine which characteristics of the caregiving situation significantly relate to increased burden.	N=100 Mean age= 60.36	Mean age=69.35	Zarit Burden (ZBI) HRQL (SF-12) Modified Barthel Index (MBI) Geriatric Depression Scale (GDS)	Caregiver burden was related to worsening caregiver mental health and an increase in caregiving hours.
Molloy et al. (2005) Scotland	Cross-sectional Aim to use Karasek's demand-control model of job strain in an attempt to extend previous work examining the psychological impact of informal caregiving in stroke.	N=138 Mean age=61.3	Mean age=67.9	Anxiety and depression (HADS)	At 2 weeks post stroke, higher caregiver demand and low control were related to caregiver depression. At 8 weeks post-stroke, caregiver perception of control over assisting recovery was more important for predicting both caregivers' anxiety

					and depression.
Peyrovi et al. (2012) Iran	Cross-sectional Aim to examine the relationship between the perceived care-related life changes and depression in family caregivers of people with stroke, and identify predictors influencing depression and perceived care-related life changes.	N=60 Mean age=60.72	Mean age=? But the age range frequency is shown	Depression Bakas caregiving Outcome Scale; Center for Epidemiologic Studies Depression Scale	Stroke survivors' functional disability significantly predicted care-related changes and depression in caregivers.
Schreiner & Morimoto (2003) Japan	Cross-sectional Aim to examine the relationship between caregiver mastery and depressive symptoms among family stroke caregivers in western Japan.	N=100 Mean age=60.4	Mean age=69.35	Depression QoL (SF-GDS-15)	Caregivers with high mastery reported significantly less burden, but more caregiver burden was related to stroke individual being more functionally dependent.

Singh & Cameron (2005) Canada	Cross-sectional Aim to test the factors associated with caregiver experiences.	N=48 Mean age=54.6	N=68.44	Emotional well-being (POMS)	Amount of stroke individual's behavioral problems was related to the caregivers' emotional well-being. Caregivers' sense of mastery moderated the relationship between caregiver satisfaction and emotional well-being.
Sit et al. (2004) Hong Kong	Cross-sectional Aim to examine aspects of social support available to family caregivers during the first 12-week transitional period following hospital discharge	N=102 Mean age= reported as range percentage	Mean age=?	Caregiver general health (GHQ) Physical health (Physical Health Index)	Stroke individual's level of functional deficits, and support was related to caregiver psychosocial health. The home care for the stroke survivor is heavy, demanding, and stressful. Around 40% of the family caregivers reported somatic symptoms. Professional advice

					and feedback in relation to home care skills were particularly lacking.
Smith et al. (2004) Scotland	Cross-sectional Aim to identify outcome measures of carer stress and coping at one year post-stroke: carer general health, anxiety, depression and perception of stress.	N=90 Mean age=57.8	Mean age=67.5	Anxiety, stress, and depression (HADS) (CADI) Caregiver general health (SF-36)	The more time spent caring for the stroke individual, the greater caregiver's stress, anxiety, and depression.
Stone et al. (2004) Scotland	Cross-sectional Aim to describe changes in personality after stroke and effects on carers.	N=35 Mean age=?	Mean age=72	Emotional disorder (HADS)	The stroke individual's personality change was related to caregiver distress.
Stone et al. (2004) Scotland	Cross-sectional Aim to describe changes in personality after stroke and effects on carers.	N=35 Mean age=?	Mean age=72	Emotional disorder (HADS)	The stroke individual's personality change was related to caregiver distress.

Thommessen et al. (2001) Norway	Cross-sectional Aim to describe the psychosocial burden experienced by informal carers of elderly stroke victims, and to identify its predictors among baseline characteristics of the patients.	N=68 Mean age=?	Mean age=77.8	Burden (RSS)	Caregiver burden was related to stroke individual's impaired cognitive function.
Van den Heuvel et al. (2001) Netherlands	Cross-sectional Aim to identify which caregivers of stroke patients living at home experience the highest levels of strain and are at risk of burn-out, and to investigate how support for caregivers of stroke patients could best be organized, and when this support should be offered.	N=212 Mean age=64	Mean age=?	Mental health and vitality (SF-36) Strain (CSI)	The severity of stroke individual's cognitive, behavioural and emotional changes were the main risk factors of caregiver burnout.

Visser-Meily et al. (2005) Netherlands	Longitudinal Aim to identify early predictors of life at 1 year after stroke.	N=187 Mean age=54	Mean age=56	Burden (Caregiver Strain Index) Life satisfaction (Life Satisfaction Checklist) Depression (Goldberg Depression Scale)	Caregivers' passive coping strategy was the strongest predictor of caregiver depression.
Visser-Meily et al. (2009) Netherlands	Longitudinal Aim to assess changes in the psychosocial functioning of spouses (burden, depressive symptoms, harmony in the relationship between patient and spouse, and social relations) during the first 3 years after stroke and identified predictors of spouses' psychosocial functioning based	N = 211 couples Mean age =54	Mean age= 56	Burden (caregiver strain Index) Depression (Goldberg Depression Scale),	The depression score showed a nonlinear increase with time. Burden, and depression were significantly related to caregiver coping strategies

	on the characteristics of patients' and spouses' coping style.				
White et al. (2003) Canada	<p>Longitudinal</p> <p>Aim to examine relationships between stroke survivor and family caregiver factors and the caregiver's health-related quality of life (HRQL) and overall quality of life (QoL) during the first and second years after stroke.</p>	<p>N=97 couples</p> <p>Mean age=56.8</p>	Mean age=73.6	<p>Health related QoL (SF-36)</p> <p>Checklist of 24 physical symptoms</p> <p>Burden Index</p>	<p>In year 2 post-stroke, poor caregiver physical and mental health and impaired communication difficulties were associated with reduced QoL.</p>

White et al. (2006)	Longitudinal Aim to examine the health-related quality of life and overall quality of life of family caregivers of stroke survivors to determine changes over time and to identify QoL predictors.	N=52 Mean age=61	Mean age=?	Health-related quality of life (SF-36) Quality of life (Stroke caregiver quality of life Measure) Mastery (Pearlin's Mastery Scale) Relationship Quality (Quality of Relationship Scale)	The most important predictors of QoL were the stroke survivors' behavioural disturbances and reintegration into normal pattern of living.
Wilz & Kalytta (2008) Germany	Longitudinal Aim to investigate prevalence rates of anxiety symptoms in stroke patients' spouses and associated factors.	N=114 couple Mean=58	Mean age=60	Beck Anxiety Inventory	An association was found between spouses' anxiety symptoms baseline, spousal gender, and patients' disability and caregivers' anxiety.

Caregiver Experiences Captured in Qualitative Studies

Across qualitative studies, there were common challenges and sources of satisfaction identified by caregivers. More in-depth information about caregiving experiences was captured in qualitative than in quantitative studies.

Caregiving Challenge. Caregivers reported that their main challenge in caring for individuals with post-stroke was in relation to their informational needs. Caregivers would have liked more information on: stroke and its effects on their loved one (Bakas & Burgener, 2002; Brereton & Nolan, 2000; Smith et al., 2004), local support services, training information provided to stroke individuals (Brereton & Nolan, 2000; O'Connell et al., 2003), and financial entitlement information (Kerr & Smith, 2001). Caregivers also mentioned several emotional concerns. Some caregivers reported a lack of emotional support (Bakas, T. & Burgener, 2002; Kerr & Smith, 2001). Caregivers' needs for emotional support were in relation to dealing with stroke individuals' behavioural and emotional changes that caused them emotional strain (Green & King, 2009) or emotional distress (Grant et al., 2004; Subgranon & Lund, 2000).

Caregiving Satisfaction. Caregivers reported pride in their accomplishments in caring for and seeing positive changes in the stroke individual (Burman, 2001; Greenwood et al., 2009; Secrest, 2000), as well as feelings of fulfillment and satisfaction (Green, Mackenzie, Cloud, & Wilson, 2009; Subgranon & Lund, 2000; McPherson, Wilson, Chyurlia, Leclerc, 2010). Caregivers reported satisfaction in being brought closer to the stroke individuals as they enjoyed helping their loved ones (Moore, Maiocco, Schmidt, Guo, & Estes, 2002; Secrest, 2000).

Across the reviewed qualitative studies, the timing of data collection varied. For some researchers, data collection with caregivers commenced at the time of the stroke. Other researchers commenced data collection at a time when family members or friends commenced

their caregiver role at time of discharge. Most studies captured caregiver experiences over the first year or less after the patient experienced a stroke. Most researchers described their studies as being comprised of convenience samples: sampling details were not provided in the reviewed articles.

In summary, qualitative studies contributed a rich and varied body of descriptive findings about the negative and positive emotions experienced by caregivers of individuals with stroke. Across the reviewed studies (Table 2.2), researchers captured the positive experiences of caregiver satisfaction (Burman, 2001; Mcpherson et al., 2010), fulfillment (Moore et al., 2002; Subgranon & Lund, 2000), and mastery of their caregiver role (Secrest, 2000). Of note, these studies also identified caregiver burden and distress that appeared to be influenced by role overload (Pierce & Steiner, 2004), social isolation (Moore et al., 2002), lack of support (Bakas & Burgener, 2002; Kerr & Smith, 2001; O'Connell, Baker, & Prosser, 2003; Smith et al., 2004), overwhelming caregiving tasks (Bakas, Austin, Jessup, Williams, & Oberst, 2004; Lee, 2004), and a lack of attention by health care professionals to the needs of caregivers (Brereton & Nolan, 2000; Lee, 2004).

Patient Characteristics

Numerous researchers have examined patient-related variables purported to influence caregivers' experiences in caring for individuals with stroke. Some of these characteristics included: patient gender, age, severity of stroke, functional status, and cognitive impairment as factors that may influence or moderate the caregiver's responses to the experience of caregiving (Lee, 2004).

Stroke patients often experience significant functional limitations, cognitive impairments, urinary incontinence, and speech difficulties following stroke. These impairments may last

indefinitely and require lifelong caregiver assistance. Even with formal assistance (i.e., from a home health aide), families are frequently faced with a multitude of stressors ranging from the coordination of medical care to 24-hour care of their loved ones. A more profound impact may be the grief associated with the changed relationship with the patient (Saban et al., 2010). This loss may be especially evident in spouses of individuals with stroke. Other studies have consistently demonstrated that family caregivers are at risk for developing depression, anxiety, sleep disturbances, poor quality of life, and health problems (Berg, Palomaki, Lonnqvist, Lehtihalmes, & Kaste, 2005; Lee, Colditz, Berkman, & Kawachi, 2003; Schlote, Richter, Frank, & Wallesch, 2006; Ski & O'Connell, 2007; van Exel, Koopmanschap, van den, Brouwer, & van den Bos, 2005) as a direct result of the functional limitations, cognitive deficits, urinary incontinence, and speech difficulties experienced by individuals with stroke.

In summary, most of the reviewed studies indicated that the functional status of individuals with stroke caused caregiver burden (e.g., Blake & Lincoln, 2000; Bugge et al., 1999; Choi-Kwon et al., 2005; Jones, Charlesworth & Hendra, 2000; Kao & McHugh, 2004; Tiegs, et al., 2006; Tooth, McKenna, Barnett, Prescott, & Murphy, 2005). Surprisingly, some studies found no significant relationship between the patients' functional status and caregiver burden (e.g., Chumbler, Rittman, Van Puymbroeck, Vogel, & Qin, 2004; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Scholte, Richter, Frank, B., & Wallesch, 2006; Tang & Chen, 2002; Thommessen, Aarsland, Braekhus, & Oksengaard, 2002). On the other hand, studies have consistently demonstrated that family caregivers are at risk for developing depression, anxiety, sleep disturbances, poor quality of life, and health problems due to the stroke patient's severity of disability and psychological changes (e.g., Berg, Palomaki, Lonnqvist, Lehtihalmes, & Kaste, 2005; Peyrovi et al., 2012; Lee, Colditz, Berkman, & Kawachi, 2003; Schlote, Richter, Frank, &

Wallesch, 2006; Ski & O'Connell, 2007; van Exel, Koopmanschap, van den, Brouwer, & van den Bos, 2005). Other studies indicated that the stroke individual's mental status or cognitive function impairment could cause caregiver burden (e.g., Chumbler et al., 2004). Moreover, there was disagreement in the literature on whether patient age and gender were correlated with increased caregiver stress (e.g., Singh & Cameron, 2005; van den Heuvel et al., 2001).

Table 2.2 Qualitative Researches on Caregiver Emotions

Author, dates, country	Sample (n) size Caregivers	Aim	Data collection	Challenges reported by caregivers	Satisfaction reported	Coping strategies reported
Bakas et al. (2002) USA	N=14 Convenience sample	Determine the need, concerns, strategies and advice desired by caregivers.	After 6 months after discharge	Need more information about stroke, emotional support, and managing behavioural problems.	None	Visiting inpatient therapy sessions; talking with caregiver and stroke individual, asking for help.
Brereton & Nolan (2000) UK	N=7 Convenience sample	Improve understanding of needs of caregiver.	2-4 years after stroke	Need more information about stroke; more attention to caregivers' needs; physical care of stroke individuals.	None	Explored information themselves; developed their routines for managing physical care.
Burman (2001) USA	N=13 Purposive sample	Explore caregiver expectations of stroke and management strategies of rural families.	6-12 months after the first stroke	Caregivers had uncertainty about loved one's future recovery, & feeling stressful about living arrangement.	Satisfaction with effective coping	Reconstituted family life, maintained family routines, getting outside help.
Grant et al. (2004) USA	N=22 Part of a RCT	Identify the major problems and associated	1 month after stroke	Safety, difficulty in managing ADLs, cognitive,	None	None

		feelings experienced by family caregiver of stroke survivors during 1 st month.		behavioural, & emotional changes in stroke individuals were the three most common problems. The most distressing problem was managing incontinence.		
Green & King, (2009) Canada	N=26 couples Convenience sample	Explore patients and wife-caregivers expending considerable time and energy reestablishing control of their lives following minor stroke in an attempt to incorporate changes to self and their relationship into the fabric of their lives.	1 year post a minor stroke	Lack of information, uncertainty, feeling open to further events, lack of control, feeling overwhelmed by the immediacy of the illness experience; coping with emotional and cognitive changes.	None	Wives reported a hyper-vigilant role to cope with caregiver stress and anxiety. Patients in this study focused primarily on their physical recovery and their perceptions of necessary changes. Wife-caregivers were actively involved in managing the day-to-day demands that stroke placed on individual, family and social roles.

Greenwood, Mackenzie, Wilson, & Cloud (2009) UK	N=31 Purposive sample	Investigate the experiences of informal carers of stroke survivors over time.	3 months post stroke	Carers experienced uncertainty when caring for stroke survivors	Carers felt they were brought closer to survivors or other family members; realization of their own inner strengths; carers and survivors took better care of their own health.	Carers adopted new routines and strategies, maintained a sense of humour, identified absolute and relative positives in life; and questioned the future as being influenced by uncertainty
Kerr & Smith (2001) Scotland	N=22 Purposive sample	Explore the experience of caregiving, focusing on the help & support required.	1 year post stroke	Problems identified included supporting the stroke individual's mobility, own lifestyle change, lack of support.	None	Discussion of issues with an "expert" and emotional support was helpful.
Lee (2004) Hong Kong	N=15 Purposive sample	Explore and describe the experience of Chinese family caregivers of stroke individuals and identify their needs.	At least 6 months post stroke	Caregivers reported anxiety, exhaustion, health problems, burden associated with ADLs, role change, financial difficulties, and lack of support.	None	Paid for outside help; some older female caregivers were less likely to seek formal or informal help.

Weaver Moore et al. (2002) USA	N=8 Part of larger study	Elicit the subjective responses of caregivers regarding caregiving	No time reported	Uncertainty about future, and having no life all the time.	Enjoyed helping stroke individual; relationship with the patient became closer	Informal support with ADL, respite, and keeping families informed.
O'Connell et al. (2003) Australia	N=14 Convenience sample	Determine caregivers' perspectives of their support & educational needs.	No time reported	Lack of information, poor availability of healthcare services, lack of continuity of care, and changes in role and relationship.	None	Sense of humour, taking time out, trying not to worry much.
Pierce & Steiner (2004) USA	N=5 Part of a larger sample	Examine the experiences of 5 men caring for women with stroke	First 3 months after hospital rehabilitation	Dealing with role and family changes, and the patients' depression; difficulty in managing the effects of stroke, such as communication problems.	Close family ties, "being there" for one another	Perseverance and prayer
Secret (2000) USA	N=10 Purposive sample	Investigate the quality or nature of life as experienced by caregivers of stroke	2-14 years since stroke	Fragility, vigilance, a sense of loss, and increased responsibility emerged; changes	Pride in positive changes in the survivor; being brought closer by a changed	None

		individuals		in the relationship with stroke patient.	relationship.	
Smith et al. (2004) Scotland	N=90 Purposive sample	Describe the experience of caregivers of stroke individuals	1 year after stroke	Caregivers felt they had insufficient information; difficulties in coping with emotional changes in stroke patients; restricted social lives, disturbed sleep, fear of leaving the loved one alone, and role changes.	Adapted by establishing a routine and accepting support, using respite, not planning for the future, adopting an attitude of taking one day at a time.	
Subgranon & Lund (2000) Thailand	N=20 Purposive sample	Examine the perspectives of family caregiver of elderly stroke patients	1 year after stroke	Managing treatment and managing difficulties.	A sense of fulfillment with the patients, doing other activities, saving the patients' life, feeling close to the patients.	Acceptance and patience, rest/relaxation, learning, time management of problems, and seeking help.

Caregiver Characteristics

Characteristics of the caregiver, such as one's personality type, social attributes, socio-demographics, and health status may influence the caregiver's emotional and/or psycho-behavioural responses to the stress of caregiving. A number of studies have included an examination of the linkage between caregiver characteristics or experiences with caregiver emotion and caregiver empathic responses.

The reviewed literature identified relationships primarily between caregiver strain or burden and caregiver characteristics, and caregivers' responses to service inputs. Caregiver age and gender were generally shown to be unrelated to increased caregiver burden (Singh & Cameron, 2005). Evidence was mixed with respect to the importance of the caregiver's relationship to the patient and caregiver burden. Among the studies, caregivers' poor mental health or stress (Bakas & Burgener, 2002; Blake & Lincoln, 2000; Hodgson, Wood & Langton-Hewer, 1996), depressive symptoms (Berg, 2005; Choi-Kwon et al., 2005; Chumbler et al., 2004; McCullagh et al., 2005), anxiety (Choi-Kwon et al., 2005; McCullagh et al., 2005; Wilz & Kalytta, 2008) and the amount of caregiving provided (Bakas & Burgener, 2002; Bugge et al., 1999; Choi-Kwon et al., 2005; Morimoto, Schreiner, & Asano, 2001; Scholte op Reimer, de Haan, Rijnders, Limburg & van den Bos, 1998; van Exel et al., 2005) were consistently linked with increased caregiver burden. The amount of time a caregiver spent helping a stroke patient, and the caregiver's health were significantly associated with the level of strain experienced (Bugge et al., 1999). In a few studies, caregiver burden had implications for the quality of service or supports provided. Caregiver training was shown to alleviate caregiver burden in two studies (McCullagh et al., 2005; King et al., 2001). Other studies suggested that increased family and social support did not minimize the burden (Chumbler et al., 2004; McCullagh et al., 2005;

Schlote et al., 2006; Tooth et al., 2005). The relative contributions of poor self-rated health, functional disability, income, and employment to the caregiver burden remain unclear.

The burden of long-term care most often falls on the families of post-stroke individuals. These families must deal with various combinations of physical, emotional, and cognitive disability in stroke individuals. Often family caregivers receive little preparation and limited formal or professional supports. Strain among family caregivers can lead to a high level of distress, which can be exhibited in a variety of ways. Depression, anxiety, lifestyle and relationship disruption, fatigue, guilt, frustration, resentment, impatience, fear, and isolation are frequently reported (Anderson, Linto, & Stewart-Wynne, 1995; Han & Haley, 1999; Hartke & King, 2002; Ilse, Feys, de Wit, Putman, & de Weerd, 2008; Macnamara, Gummow, Goka, & Gregg, 1990; Periard & Ames, 1993; Williams, 1993). Other researchers have found that more depressive symptoms and feelings of anger among family caregivers were associated with the increased potential for harmful behaviours of the caregivers (e.g., a precursor to elderly mistreatment; MacNeil et al., 2010). Caregivers may be less likely to acknowledge their anger in research or social service interviews because of their shame in having these feelings or fear of social or legal scrutiny (Gallagher-Thompson, Lovett, & Rose, 1991).

Overall, the psychosocial consequences of caregiving have been well documented. For example, empirical efforts have examined relationships among caregiver burden, depression, resentment, and formal care provision. However, consequences of negative emotions held by caregivers in their delivery of care to patients with stroke have received little research consideration. These consequences might include caregivers' empathic helping behaviours as influenced by patient and caregiver characteristics (e.g., age, gender, and emotions such as caregiver depression, anger, and satisfaction) that warrant further study.

Empathy in Caregiving

The term ‘empathy’ refers to sensitivity to, and understanding of mental states of others. Hollin (1994) has described “the ability to see the world, including one's own behaviour, from another person's point of view is to display empathy" (p. 1240). Eisenberg and Strayer (1987) described empathy as "an emotional response that stems from another's emotional state or condition and that is congruent with the other's emotional state or situation" (p.5). As these definitions illustrate, the term empathy has been used to refer to two related human abilities: mental perspective taking (also known as ‘cognitive empathy’) or the drive to identify another's mental states as explained by Rogers (1959) and the vicarious sharing of emotions (also known as emotional empathy) (Davis, 1994; Staub, 1987). In attachment theory, authors mentioned that the caregiving system provides an appropriate context for the study of compassion and altruism (Mikulincer, Shaver, Gillath, & Nitzberg, 2005). Caregiving is a set of behaviours that involves a relationship between the caregiver and the care receiver to meet the care receiver’s needs. In order to achieve a successful caregiving relationship, empathy is the key mechanism that facilitates the caregiving process to meet the needs of those who are afflicted or suffering.

Due to the complex consequences of stroke, the caregiver can be overwhelmed by the physical and emotional burdens of the caregiving process. Over time, and influenced by a sustained caregiving burden, the caregiving situation has the potential to cause a lack of empathic responses by caregiving families toward patients. Sebern’s (2005) study of “shared care” addresses interactions that require the caregiver’s cognitive ability to communicate, make decisions, and engage in reciprocal actions with patients that is driven by empathy. Further study of the linkage between family caregiver empathic responding and their emotional states is warranted. Empathic family caregivers are critical in managing the complications of stroke and

providing supportive and sensitive care toward patients. Family caregivers need to be supported in attaining satisfaction with the type of care they provide to patients. The key to optimal caregiving for patients is good communication that is driven by empathic responding by family or friend caregivers. Empathic responding involves caregiver responses that take into account the subjective viewpoint of the patient and his or her experience with suffering.

Emotional empathy is the ability to, not only detect what others feel, but also to experience their emotions (Davis, 1994). Cognitive empathy is the ability to imaginatively or mentally comprehend with accuracy another person's thoughts and feelings (Davis, 1994). Cognitive and emotional empathy remain common concepts that are studied in the field of social psychology. However, today cognitive and emotional empathy are also studied in health care. In the healthcare literature, empathy is referred to as sensitive responses by physicians to patients, and by nurses to patients (Silverman, Kurtz, & Draper, 2005). More specifically, the use of empathy in health care studies often involves an examination of healthcare professionals' understanding of the experiences and emotions of patients toward their illness (Silverman, Kurtz, & Draper, 2005). However, there is a paucity of empirical literature that examines empathic responses in the patient and family caregiver relationship. Due to our aging population that is living longer with chronic illness, family caregivers are becoming more important partners in health care (Family Caregiver Alliance, 2012). With empathy being a hallmark of optimal health care, it is crucial for researchers and clinicians to better understand empathy in the family caregiving process: that is, how family caregivers engage in empathic processes to better comprehend and meet the needs of loved ones dealing with chronic condition, such as post-stroke, in the community.

Empathy in Psychology

The psychologist Edward Titchener introduced the term “empathy” in 1909 into the English language as the translation of the German term, “Einfühlung” (or “feeling into”). By the end of the 19th century, empathy was understood in German philosophical circles as an important category in philosophical aesthetics (Stueber, 2008). Kohler (1929) was one of the first to argue that “empathy” needs to be understood in a more cognitive vein. Rather than continuing to focus on “feeling into” the experiences of another, Kohler held that empathy was more about the ‘understanding’ of the other’s feelings than a ‘sharing’ of them. Later, two clinical psychologists, Carl Rogers and Heinz Kohut, became pioneers in the study of the phenomenon of empathy (Bohart & Greenberg, 1997). After World War II, a great interest in empathy research developed in the field of psychology. This research in empathy mostly involved attempts to test Rogers’ hypothesis that three therapeutic conditions – unconditional positive regard, empathy, and genuineness – were necessary and sufficient for therapeutic change. In summary, Rogers’ (1957) idea was that clients who received empathic understanding would be better able to trust and understand themselves and to make behavioural changes in positive directions.

On the other hand, Kohut (1984) defined empathy on two different levels: one being about abstract understanding and the other about clinical application. At the most abstract level, Kohut (1984) viewed empathy as “vicarious introspection”. In a more applied definition, Kohut (1984) stated that empathy “is the capacity to think and feel oneself into the inner life of another person” (p.82). While most approaches have focused on what is going on inside the empathizer, some researchers have studied the whole process that is taking place between the empathizer and the target. For instance, Barrett-Lennard’s (1981), as well as Davis’s (1994) conceptualizations of empathy commonly shared the division of empathy into different activities which occur at

different points in time and have a cause-effect relationship with each other. Four themes appeared repeatedly in the empathy literature and thus seem to be central to the phenomenon: understanding, emotion, perceived similarity, and concern. The majority of researchers seemed to agree that empathy includes a cognitive (or understanding) dimension and an affective (or experiential dimension), and is positively related to concern. Although the role that the empathizer's similar experiences may play with regard to empathy is inconclusive, many researchers acknowledged its relevance to the empathy phenomenon (Hakansson & Montgomery, 2002).

Empathy in Health Care

Empathy and Professional Care Providers. Effective communication in patient-centered medical consultations focuses on the patient's perspective of the situation that is addressed alongside the presenting symptoms of the patient (Little et.al, 2001). The central goals of patient-centered care are professional rapport between the doctor and the patient, and a therapeutic alliance that is based on trust and cooperation. Rapport, trust, and cooperation can only be established through a shared understanding of the patient's perspective (Tjørnhøj-Thomsen, 2009). Indeed, empathy is believed to significantly influence patient satisfaction, adherence to medical recommendations, clinical outcomes, and professional satisfaction (William & Stickley, 2010).

In the daily practice of nursing, nurses need to understand patients' feelings in order to sensitively address their concerns and assist patients to achieve wellbeing. Nursing education has focused upon behavioural techniques by students who must demonstrate empathy toward patients and their families. In the current nursing literature on empathy, authors have implored nurse educators to consider the use of educational interventions that explicitly facilitate

emotional development, as well as enable students to develop their own innate empathic capacity and self-empathy awareness to promote patient-focused, family-centered care (Brunero, Lamont & Coates, 2010).

Empathy and Family Caregiver Responses. Several experiments in social psychology have shown that empathy enhances helping and cooperation (e.g., Batson & Ahmad, 2001; Batson et al., 1995). As such, empathy is likely to motivate helping behaviour of individuals toward those who suffer or are in situations of need. Also, other research has shown that in order for empathy to affect helping behaviour, three conditions must be met: (a) perception of an individual who is in need; (b) cognitive imagination of the individual's situation of need and emotions (Batson, 1991; Batson, Early, Salvarani, 1997; Batson et al., 1996; Davis, 1994); and (c) the observer individual must be aware of the difference between one's own state and the possible state of the individual in need (Batson, 1991; Clark & Word, 1972; Darely & Latane, 1968; Davis, 1994).

In health care and health psychology literature, empathic behaviours of caregivers have been positively linked to patients' enhanced coping with illness (Coyne & Bolger, 1990; Lobchuk & Bokhari, 2008) and lower levels of psychological distress in patients (Ell, 1996; Lobchuk & Bokhari, 2008). However, most of the studies have been cross-sectional studies, which made it difficult to determine the direction of causality between psychological distress and empathy of caregivers. Empathy was measured as an independent variable that influences psychological distress and coping. Positive emotional support is an important element in managing interpersonal conflict (O'Brien & DeLongis, 1996), as well as in improving patient self-esteem and perceived control (Norton et al., 2005). On the other hand, the lack of empathic support by family caregivers may disturb the caregiving relationship. For instance, according to

Dr. Weiner's (1986) attribution theory, it is plausible for caregivers to hold negative attributions of judgment and blame toward the individual with stroke, especially if the caregiver felt that the patient's previous actions caused the condition (e.g., smoking cigarettes or poor diet). According to attribution theory (Weiner, 1986), caregivers' negative judgments of blame and negative emotions of anger can have a direct impact on the caregiver's empathic responses and helping behaviour. In other words, the caregiver's negative or positive emotions toward the patient can have a direct impact on the caregiver's empathy toward the affected individual (Lobchuk, McClement, McPherson, & Cheang, 2012). To further explain, if the caregiver thought that the stroke was caused by the patient's choice of an unhealthy diet (i.e., a diet that increased his or her cholesterol levels; which is known to be a risk factor of stroke), the caregiver could be less motivated to engage empathically with the patient, which, in turn, interferes with the supportive caregiver role. In other related studies, it has been reported that caregivers with high cognitive empathy tended to appraise the caregiving situation as less stressful or less threatening, were less depressed, and reported a higher life satisfaction than did caregivers with low cognitive empathy (Lee, Brennan & Daly, 2001). The importance of caregiver empathy in helping relationships has been found in many studies conducted by nurses and other health care researchers (LaMonica, Wolf, Madea, & Oberst, 1987; Mehrabian, Young & Sato, 1988; Raudonis, 1993; Reid-Ponte, 1992). In trusting relationships between patients and professional or family caregivers, empathy has been identified as a key ingredient (Barrett-Lennard, 1981; Carkhuff, 1969; Kalisch, 1971; LaMonica, Carew, Winder, Haase & Blanchard, 1976) that increases the effectiveness of helping behaviours (LaMonica, Wolf, Madea, & Oberst, 1987). On the other hand, inadequate levels of cognitive empathy in caregivers were found to influence their effective adjustment to caregiver stress, which likely had a negative impact on helping relationships (Roberts, 1991). In the study

by Lee, Brennan, and Daly (2001), a caregiver's cognitive empathy was significantly related to stress appraisal, threat appraisal, depression, and life satisfaction.

In summary, the researcher's review of the empathy literature in nursing, health care, and health and social psychology consistently found the significance of empathy in helping relationships. Moreover, study findings of relationships that existed among the patient's illness situation or functional status, the caregiver's emotional responses to the patient's situation, and empathy in caregivers (in both health care providers and family caregivers) established a foundation for further systematic testing of relationships among these variables in the caregiving context of stroke care.

CHAPTER THREE: METHODOLOGY

Given the paucity of research investigating the linkages among the caregiver's perception of the patient's functional limitations following a stroke, the caregiver's emotional states, and the caregiver's empathy-related responses, a descriptive correlational study was judged to be the most appropriate type of investigation to pursue. This chapter explains the research design and methodology used in this study. The research design, sample, setting, data collection method, and instrumentation are described in the following sections. In addition, ethical considerations are discussed.

Design and Method

This study employed a correlational descriptive research design. First, a correlational approach was undertaken to test associations among the caregiver's perception of the patient's level of functional deficit, the caregiver's emotions, and the caregiver's empathic responses toward patients with stroke. Second, based on the noted bivariate correlational analysis, the researcher aimed to examine whether the caregiver's report of the patient's level of functional deficits and the caregiver's emotions were predictors of the caregiver's empathic responses toward the post-stroke patient.

Research Questions

The following questions were addressed in this study.

1. What is the relationship between the patient's functional deficits and the caregiver's emotional or psychological states?
2. What is the relationship between the caregiver's emotional or psychological states and the caregiver's empathy-related helping behaviour?
3. What is the relationship between the patient's functional deficits and the caregiver's

empathy-related helping behaviour?

4. Are the patient's functional deficits and the caregiver's psychological or emotional states predictive of the caregiver's empathy-related helping behaviour?

Protection of Human Rights

Written ethical approval from the Education and Nursing Ethics Review Board at the University of Manitoba and written access approval from the Riverview Health Centre (RHC) were obtained prior to commencing recruitment and data collection. In addition, verbal approval from the administrator (Mr. Russ Down) of the Stroke Recovery Association of Manitoba (SAM) was obtained to recruit eligible family member participants from their caregiver support group.

In the invitation letters to family caregivers (Appendix A & B) and informed consent form (Appendix C), family caregiver participants were advised and informed of their voluntary right to participate in this study without risk of penalty. All participants received written information about the study in the informed consent form about the nature of the study and confidentiality of their responses. In the study, 14 eligible participants expressed their interest in the study. After the researcher contacted eligible participants by telephone, all participants chose to complete the questionnaires at home. Therefore, both the informed consent form and questionnaires were sent by postal mail to the eligible participants. One of 14 eligible participants declined participation in the study by returning the informed consent form marked "declined". Therefore, only 13 participants returned the signed informed consent forms and their responses to study questionnaires to the researcher.

The process of sample recruitment took into consideration the potential participants' right to decline without any knowledge by the researcher of this decision at both recruitments sites (RHC and SAM). The first point of contact was the receptionist at the post stroke clinic at the

RHC (i.e., Ms. Critchlow) and Mr. Down at the SAM. The researcher had no knowledge as to which eligible family caregivers received an invitation letter to the study. Only the eligibility criteria for family caregivers were provided to the key contacts at both recruitment sites. All family caregivers who received a letter of invitation were instructed by the key contacts to return the reply to either the clinic clerk at RHC or the key contact at SAM indicating their desire to speak further with the researcher about the study. If family caregivers wanted to speak further with the researcher, they left their name and contact information (e.g., a telephone number) on the invitation for the researcher to reach them by telephone. All returned responses to letters of invitation were retained in individual envelopes that the researcher retrieved on a weekly basis from the key contacts who were not able to see the responses.

The informed consent letter provided contact information for the researcher, the thesis supervisor and the Human Ethics Committee. A second copy of the consent form was also provided to participants for their records. Participants were informed in the informed consent form of their right to confidentiality and privacy, as well as how this right was being protected by the researcher. Key contacts who assisted with the recruitment of participants were not informed of which family caregivers had agreed or declined to participate in research. This process protected participants from any influence on services they were currently receiving at the respective recruitment sites. Participants were informed that any information they provided would be presented as ‘grouped’ data in written reports and in any publications of findings arising from this study. This action assisted in providing anonymity.

To maintain confidentiality, participant responses were assigned a code. The master list that linked participant names and assigned codes was kept separate in a locked filing cabinet in the researcher’s home. Only the researcher had access to the participants’ names. All efforts were

made to ensure that participants' signed informed consent forms and completed questionnaires were secure in the researcher's home. Seven years after the completion of the study, the data will be destroyed via confidential waste. Only the researcher has access to the signed informed consent forms and collected data on the study's questionnaires.

There was no deception or coercion associated with any of the procedures. The caregivers were not compensated in any way for their participation in the study. Time was the primary investment required by the caregiver participants. There were no perceived legal or social risks for the caregiver participants and there were no major harmful effects evidenced in caregivers who participated in the study. The researcher did not observe any personal distress arising in family caregivers as a result of having participated in this study.

Recruitment Protocol

The researcher provided key contacts at Riverview Health Centre Rehabilitation Outpatient Clinic and at the SAM with a list of inclusion criteria for family caregivers who were eligible as participants in the study.

Site A: Riverview Health Centre (RHC), Rehabilitation Outpatient Clinic. The key contact at Riverview Health Centre was Ms. Elsa Critchlow, Office Assistant. Ms. Critchlow provided eligible family caregivers or post stroke patients attending the Rehabilitation Outpatient Clinic with a letter of invitation (Appendix A) from the researcher that described the study and the family caregiver's role as a potential participant in the study. The key contact also instructed eligible participants to return the letter of invitation to the clinic clerk to indicate their agreement (or not) to speak with the researcher about the study. The key contact would not know who declined to speak further with the researcher about the study. All returned responses to letters of invitation were kept in an envelope that the researcher retrieved on a weekly basis from Ms.

Critchlow at RHC.

Site B: Stroke Recovery Association of Manitoba (SAM). The key contact at the SAM was Mr. Russ Down (administrator). Mr. Down provided eligible family caregivers or post stroke individuals who were participants in the support group with a letter of invitation (Appendix B) that described the study and the family caregiver's role as a potential participant in the study. Mr. Down also instructed eligible participants to return the letter of invitation (Appendix B) to him to indicate their agreement (or not) to speak with the researcher about the study. Mr. Down did not know who declined to speak further with the researcher about the study. All returned responses to letters of invitation were retained in an envelope that the researcher retrieved on a weekly basis from Mr. Down at the SAM.

Sample and Setting

The target population for this study was family caregivers of individuals with stroke after discharge from hospital or a rehabilitation facility in the City of Winnipeg in Manitoba, Canada. The aim of this study was to have 20 caregivers comprise the sample for this study. This sample size was based on the recommendation of the researcher's thesis committee (Dr. Michelle Lobchuk, Supervisor, Faculty of Nursing, University of Manitoba, Dr. Wanda Chernomas, Internal Member, Faculty of Nursing, University of Manitoba, and Dr. Sepideh Pooyania, External Member, Assistant Professor, Medicine/Physical Medicine and Rehabilitation, University of Manitoba and Riverview Health Centre). The thesis committee recommended that a sample size of 20 family caregivers would be appropriate for a small pilot study as part of the researcher's thesis project (University of Manitoba, Faculty of Nursing).

All family caregivers who were primary caregivers of non-institutionalized stroke patients were recruited over a five month period from October 2012 to February 2013 at

Riverview Health Centre (RHC) in the City of Winnipeg and the Stroke Association of Manitoba (SAM).

Inclusion Criteria for Stroke Caregivers. To be included in the study, family caregivers met the following criteria: (a) must identify themselves as the primary caregiver involved in the care of the medically diagnosed individual dealing with their first stroke or multiple strokes in the home setting (biological, legal, or functional relationships), (b) must be able to speak, read, and write the English language, and (c) must have cared for individuals who experienced their first stroke or multiple strokes at least three months prior to the time of participating in this study. These criteria were chosen to obtain a homogeneous group of participants with comparable experiences caring for individuals dealing with a first-time stroke or multiple strokes.

Feasibility of Recruitment. In the RHC Outpatient Clinic, according to Dr. Pooyania (personal communication, May 13, 2012), approximately 150 patients and accompanying family caregivers were seen in her clinic in 2011. At the SAM, there were approximately 10 family caregivers participating in the SAM support group in October 2012 (Mr. Russ Down, personal communication, December 8, 2012).

Data Collection

If family caregivers agreed to participate in the study and provided their contact information (e.g., telephone number), the researcher contacted them by telephone to further explain the study and their role in the study. The researcher explained that, as part of the study, potential participants would be asked to read and complete a written informed consent form (Appendix C) before they completed four questionnaires on a one-time basis. The researcher provided family caregivers with several options to complete this study's questionnaires. First,

caregivers could choose to complete the questionnaires by themselves and then mail their written informed consent form and responses to the study questionnaires to the researcher in a sealed, pre-stamped, addressed envelope marked confidential that was provided to them. Second, caregivers could choose to schedule a face-to-face or telephone meeting with the researcher to complete the written informed consent and study questionnaires at a date, time, and place that was convenient to them.

After completing the informed consent, the study participants completed four study instruments including: the researcher-developed Caregiver Demographic Questionnaire, the Stroke Impact Scale (Duncan, Bode, Lai, & Perera, 2003), the Profile of Mood States (Heuchert, & McNair, 2012), and the Empathic Responding Scale (O'Brien & Delongis, 1990) which will be described more fully below. Study participants were instructed not to share their responses with individuals dealing with stroke when participants completed the study questionnaires on their own in their homes. All 13 participants completed their questionnaires on their own and mailed their responses back to the researcher. One of these participants had missed data in one of the sections in the Stroke Impact Scale. The researcher called this participant about the missed data. The participant stated she was planning to go back to the section, and then got distracted. The researcher ensured there was no post-stroke individual present during the telephone conversation. The participant successfully provided the missed responses with the researcher by telephone.

Instruments

Caregiver Demographic Questionnaire. The Caregiver Demographic Questionnaire was a researcher-developed demographic data tool that contained 11 items. The questions were about the age of caregivers and the patient (e.g., “What is the patient’s age?” and “What is your

age?”), and the caregiving relationship (e.g., “How long have you been taking care of the patient (months)?”) (Appendix D).

Stroke Impact Scale. The Stroke Impact Scale (SIS) (Appendix E) was developed to capture dimensions of health related quality of life affected by stroke: emotion, communication, memory and thinking, and social role function (Duncan, Bode, Lai, & Perera, 2003). The SIS was developed at the University of Kansas Medical Center and was based on feedback from patients and their caregivers. It measured various aspects of stroke recovery which were found to be important to patients and caregivers, as well as to stroke experts. After intensive psychometric testing, the 59- item Stroke Impact Scale Version 3.0 was developed. The 59 questions of the SIS were broken down into eight small categories: strength, hand function, mobility, activities of daily living, emotion, memory, communication, and social participation, then author grouped in five main domains which were Physical, Emotional, communication, social participation, and memory. Although the SIS was a patient-based self-report scale, there is also a proxy version of the tool that was employed in this study with family caregivers to capture their perceptions of the patient’s health-related quality of life. Each item was rated on a five-point Likert-type scale in terms of the level of difficulty the caregiver perceived that the patient experienced on five health-related quality of life dimensions. The health-related quality of life items asked caregivers to rate the patient’s functional status with questions such as: “How difficult is it for him/her to remember things that happened yesterday?” (Appendix E). A score of 1 represented the patient’s inability to complete different tasks and a score of 5 represented no difficulty experienced at all in health-related quality of life dimensions of the patient. Summative scores were generated for five health-related quality of life domains. Domain scores could theoretically range from 0 to 100 units. Lower scores meant higher negative impact on the patient’s health-related quality of life.

The last question was a different measurement with other questions which it was included to assess post-stroke individuals' overall perception of recovery and was presented in a visual analog scale ranging from 0 to 100: 0 = "no recovery" and 100 = "full recovery".

The SIS version 3.0 is also available in a proxy version to be used when patients are unable to complete the tool (Duncan et al., 2002). The SIS version 3.0 (proxy version) was employed with family caregivers in this study. Duncan et al. (2002) had compared patient and proxy ratings of the mailed SIS. Fifty-six of 125 of the returned surveys were completed by or with the assistance of proxy respondents. The intra-class correlation coefficients ranged from adequate to excellent (ICC = 0.50 to 0.83). Agreement was strongest in domains rating observable behaviours. In five out of eight categories, patients rated themselves as less affected on health-related quality of life than did the proxy raters on patient health-related quality of life. The magnitude of the bias is reported as small and without clinical meaning (Duncan et al., 2002). The SIS proxy version 3.0 had adequate to excellent correlations with the Mini-Mental Examination, Barthel Index, and Lawton Instrumental Activities of Daily Living and the Motility Index (Duncan et al., 2002) indicating excellent construct validity of the SIS tool.

Profile of Mood States (POMS). To capture family caregivers' self-reports of their mood states, the researcher employed the Profile of Mood States (POMS). The POMS was developed in 1964 (McNair, Lorr, & Droppleman, 1971). The POMS 2 short version (Appendix F) is a revision of POMS which contained 35 items (Heuchert, & McNair, 2012). The short version used 5-point interval scales to measure seven mood states: tension, depression, anger, vigor, fatigue, friendliness, and confusion: "0" (not at all) to "4" (Extremely). Family caregivers provided a self-report on each mood state item during the caregiving process and included questions such as: "How you have been feeling during the past week (Tense or Cheerful etc.)

(Appendix F)?” Higher scores indicated more of each mood state. A total mood disturbance score (TMD) was calculated based on six mood states except friendliness which captured the caregiver’s mood states in general.

The POMS short version provided a rapid, economical method of assessing transient, fluctuating active mood states of caregivers over the previous four weeks. Regarding internal consistency estimates, the POMS had been used in the study of psychosocial factors and the quality of life in men treated with brachytherapies for prostate cancer (Lev et al., 2004). These investigators reported that the Cronbach's alpha reliability for the using the scale in this study was 0.93 (Lev et al., 2004). In another study involving 102 non-disabled community-dwelling elders aged 65 years and older, the alpha coefficients for six mood state sub-scales ranged from 0.73 to 0.89 (Jette et al., 1996). Chen, Snyder, and Krichbaum (2002) employed the Chinese version of the tool with a sample of 80 Taiwanese community-dwelling elders and found higher alpha coefficients, ranging from 0.98 to 0.99 for six mood state sub-scales on the POMS short version (Chen, Snyder, & Krichbaum, 2002).

The Empathic Responding Scale (ERS). To capture the family caregiver’s self-report on empathic responses toward the patient, the researcher adapted the Empathic Responding Scale (Appendix G) with permission from one of the tool’s developers (A. DeLongis, personal communication, February 2, 2012). The ERS consisted of ten, 5-point interval questions, ranging from 0 (does not describe me well) to 4 (does describe me well). Each item captured the caregiver’s perception on how well the caregiver understood the patient, and included questions such as: “How well do you try to understand patient’s concerns?”(Appendix G). In a sample of undergraduate psychology students, the Cronbach’s alpha coefficient of 0.93 was reported (O’Brien & Delongis, 1996). In the study of interpersonal dimensions of stress and coping by 82

married couples living in a step family context, the Cronbach's alpha coefficient was 0.89 (O'Brien, DeLongis, Pomaki, Puterman, & Zwicker, 2009). Bokhari (2006) captured ovarian cancer patients' perception of their caregivers' empathic behaviour on the ERS that had excellent reliability with a Cronbach's alpha coefficient of 0.93. Hansen (2009) also employed the tool with family caregivers of patients dealing with smoking and non-smoking related disease. In Hansen's study, Cronbach's alpha coefficients ranged from .80 for family caregivers in the smoking-related group and .71 for caregivers in the non-smoking related group.

These four tools employed in this study took approximately 20-30 minutes to complete by caregiver participants in this study. All questionnaires were completed by participants at home. The wording in these tools was easy for caregiver participants to understand and there were no difficulties reported by caregivers in completing this study's questionnaires on their own.

Summary

This thesis chapter outlined the method that was used to carry out a quantitative study design aimed at exploring the associations among the caregiver's report of the post-stroke individual's functional status, the caregiver's mood or emotional states, and the caregiver's empathic responding behaviour toward the person with stroke.

The conceptual framework by Davis (1994) was used as a guide of the researcher's analyses of relationships among the main study variables: caregiver perceptions of patient functional status, caregiver mood or emotional state, and caregiver empathic responding toward the patient. Based on significant bivariate associations among the variables, a multiple regression of factors such as sociodemographic factors of caregivers, patient functional status, and caregiver mood state on the criteria variable of caregiver empathic responding behaviour was planned.

CHAPTER FOUR: RESULTS

The purpose of this study was to identify and assess relationships among functional deficits of individuals dealing with post-stroke, the family caregiver's emotions (psychological distress), and family caregivers' ability to empathize with post-stroke individuals. The specific research questions addressed in this study were:

1. What is the relationship between the patient's functional deficits and the caregiver's emotional or psychological states?
2. What is the relationship between the caregiver's emotional or psychological states and the caregiver's empathy-related helping behaviour?
3. What is the relationship between the patient's functional deficits and the caregiver's empathy-related helping behaviour?
4. Are the patient's functional deficits and the caregiver's psychological or emotional states predictive of the caregiver's empathy-related helping behaviour?

Introduction

This chapter describes the demographic information of family caregivers of individuals dealing with post-stroke and the relationship between family caregivers and post-stroke individuals. Statistical analyses of the research questions are presented in conjunction with a report of the major findings.

Data for this study were collected over a five-month period between October 2012 and February 2013. Two sites for recruitment of subjects included in this study were: the outpatient clinic of the Day Hospital at Riverview Health Centre, and the Stroke Recovery Association of Manitoba. Instruments employed to collect data from each of the participants included the Caregiver Demographic Questionnaire, the Stroke Impact Scale (proxy version) (Duncan, Bode,

Lai, & Perera, 2003), the Profile of Mood States (Heuchert, & McNair, 2012) scale, and the Empathic Responding Scale (Caregiver Perspective of Own Empathic Behaviour) (O'Brien & Delongis, 1990).

The analyses of data to address the four research questions involved a variety of statistical tests as determined in consultation with the statistician located at the Manitoba Centre for Nursing and Health Research (MCNHR) (Mr. Brendon Dufault, MCNHR March 14, 2013). The computer package SPSS 21.0 for Windows was used to analyze the data. The Cronbach's alpha coefficient, a widely used indicator of reliability according to Polit and Beck (2004), was reported for all instruments prior to addressing the research questions in the current study.

Description of the Study Sample

Overall, 50 eligible stroke caregivers were invited by key contacts from two recruitment sites. At the outpatient clinic at Riverview Health Centre, 30 invitation letters were provided to caregivers by the key contact: six (20%) caregivers agreed to participate in the study. At the Stroke Recovery Association of Manitoba, invitation letters were distributed to 20 eligible caregivers by the key contact: seven (35%) caregivers agreed to participate in the study. Thirty-five eligible stroke caregivers did not volunteer a reason for refusing to participate, one caregiver declined participation after initially agreeing to participate, and another caregiver did not participate due to the hospital admission of the patient (Table 4.0). The overall participation rate in this study was 26% (13 of 50 invited participants agreed to participate).

Table 4.0 Reasons for non-participation of patients (n = 37)

A. Recruitment difficulty	Number of Caregivers
Declined after accepting invitation (declined consent form)	1
Hospital admission	1
B. Declined invitation to participate (not returned invitation)	32
Declined without reasons (returned invitation)	3
TOTAL	37

A convenience sample of 13 caregivers comprised the study population consisting of six caregivers from the outpatient clinic at Riverview Health Centre and seven caregivers from the Stroke Recovery Association of Manitoba.

Demographic characteristics of participating caregivers and post-stroke individuals (as reported by caregivers) are fully described in Table 4.1. According to the information provided by caregivers, the mean age of post stroke individuals was 58.15 years (SD = 10.91, range = 44 to 79 years). At the time of interview or questionnaire completion, ten (76.9%) caregivers reported that the patient had experienced one stroke; two (15.4%) caregivers reported that the patient had experienced a second stroke, and only one (7.7%) caregiver reported that the patient had had more than two strokes.

The average age of caregivers was 59.92 years (SD = 16.93, range = 18 - 79 years). All

caregivers lived with post-stroke individuals. The majority of caregivers ($n = 11$, 84.6%) reported that English was their first language. The large proportion of study participants was female. In the current study, 69.2% ($n = 9$) caregivers were women.

Table 4.2 describes characteristics of the caregiving relationship as reported by caregivers in this study. Eight-five per cent ($n = 11$) of the caregivers identified themselves as spouses of the post stroke individual, 7.7% ($n = 1$) were the child of the post stroke individual, and 7.7% ($n = 1$) identified themselves as a parent of the post stroke individual. Most caregiving relationships between participants included in this study extended over 24 months. In the study, 76.9% ($n = 10$) of the caregivers reported that they either “always” or “frequently” assisted post- stroke individuals to cope with stroke. Sixty-two percent ($n = 8$) of the caregivers stated that they and the patient either “frequently” or “usually” talked openly about the patient's thoughts and feelings in regard to post-stroke individuals’ stroke. Eight-five percent ($n = 11$) of the caregivers reported that they either had “some knowledge” or a “very well” perception of knowing how the patient thought or felt about his or her stroke.

Table 4.1 Demographic Data of Caregivers and Post Stroke Individuals

Characteristic	Total Sample (n=13)	Percentage
Patient Age Range (years)		
44-59	8	61.5%
60-79	5	38.5%
Mean = 58.15		
Caregiver Age Range (years)		
18-60	6	46.2%
61-79	7	53.8%
Mean = 59.15		
Caregiver Gender		
Female	9	69.2%
Male	4	30.8%
Language		
English	11	84.6%
Others	2	15.4%
How many times has your loved one experienced a stroke?		
First time	10	76.9%
Second time	2	15.4%
More than two times	1	7.7%

Table 4.2 Caregiving Relationship Data

Caregiving relationship	Total Sample (n = 13)	Percentage
Relationship with the patient.		
Spouse	11	84.6%
Child	1	7.7%
Parent	1	7.7%
Length of Time Caregiver Caring for the patient?		
6-24 months	3	23.1%
More than 24 months	10	76.9%
Degree of Contact with the Patient		
Daily, I live with the patient.	13	100%
Extent to which you assist the patient coping with his/her stroke.		
Never/ Sometimes	3	23.1%
Frequently/Always	10	76.9%
Do you and the patient talk openly about what the patient's thoughts and feelings are in regard to his/her stroke?		
Never/ Rarely/ Sometimes	5	38.5%
Frequently/ Usually	8	61.5%
How well do you think you know how the patient thinks or feels about his or her stroke?		
Not very well	2	15.4%
Have some knowledge	4	30.8%
Very well	7	53.8%

Instrument Reliability

According to Polit and Beck (2004), the reliability coefficient is an important indicator of an instrument's quality. Thus, knowledge regarding an empirical instrument's reliability is of utmost importance when conducting and analyzing research. The Cronbach's alpha coefficient is the most frequently utilized measure of reliability and internal consistency (Cronbach, 1951). The alpha value varies between 0 and 1. The closer the alpha is to 1, the greater the internal consistency of items in the instrument being assessed (George & Mallery, 2003). Higher values of alpha are more desirable. A commonly accepted rule of thumb for describing internal consistency using Cronbach's alpha is as follows: when $\alpha \geq 0.9$, it means excellent internal consistency; when $0.8 \leq \alpha < 0.9$, it means good internal consistency; when $0.7 \leq \alpha < 0.8$, it means acceptable internal consistency; when $0.6 \leq \alpha < 0.7$, it means questionable internal consistency; when $0.5 \leq \alpha < 0.6$, it means poor internal consistency; when $\alpha < 0.5$, it means unacceptable internal consistency (George & Mallery, 2003; Kline, 1999).

The Stroke Impact Scale (SIS) (proxy version) was employed to capture post-stroke individuals' functional status after having stroke from the caregivers' perspective. In the current study, the internal consistency reliability for the Stroke Impact Scale as employed with caregivers of post-stroke individuals was 0.97.

The Profile of Mood States (POMS) was employed to capture the caregiver's emotional or psychological states. In the current study, the internal consistency reliability for the POMS as employed with caregivers of post-stroke individuals was 0.86.

The Empathic Responding Scale (ESR) was used to capture the caregiver's empathy-related helping behaviours toward post-stroke individuals. In the current study, the internal consistency reliability for the Empathic Responding Scale as employed with caregivers of post-

stroke individuals was 0.90. Overall, these results indicate that all instruments employed in this study were highly reliable.

Descriptive Analysis of Caregivers' Responses on the Study's Instruments

Stroke Impact Scale (SIS) (proxy version)

As described in Chapter Three, the Stroke Impact Scale (SIS) was developed to assess the following dimensions of health related quality of life: physical, emotion, communication, memory and thinking, and social role function (Duncan et al., 1999). The 59 questions in the SIS version 3.0 (proxy version) were evaluated by scoring each domain according to Duncan's instructions. Lower scores on the SIS dimensions meant a higher negative impact on quality of life (Duncan, 2011). The theoretical ranges of scores on SIS were calculated as individual domains: Physical sub-scale (range 0 to 100 units), Emotion (range 0 to 100 units), Communication (range 0 to 100 units), Memory and thinking (range 0 to 100 units), and Social role function (range 0 to 100 units) (Table 4.3). The physical domain consisted of four sub-categories of items that included strength, hand function, mobility, and activities of daily living. The mean score of the physical domain was 52.91 (SD = 30.41). The mean score of the communication domain (consisting of seven categories of items) was 78.30 (SD = 23.44). The mean score of the social role function (consisting of eight categories of items) was 57.93 (SD = 29.69). The mean score of the memory domain (consisting of seven categories of items) was 70.05 (SD = 21.00). The mean score for the emotion domain (consisting of nine categories of items) was 59.83 (SD = 24.57). Comparing the means of each domain, the physical domain had the lowest mean score. In other words, caregivers perceived that stroke had the highest impact on the physical function of post-stroke individuals. The communication domain had the highest

mean score. In other words, caregivers perceived that stroke had the least impact on the post-stroke individual's communication function.

Table 4.3 Descriptive Statistics of Caregiver Reports of Impact of Stroke on Patients

	N	Minimum Score	Maximum Score	Mean Score	Std. Deviation
Emotion	13	13.89	91.67	59.83	24.57
Memory	13	46.43	100.00	70.05	21.00
Communication	13	32.14	100.00	78.30	23.44
Social Participation	13	6.25	100.00	57.93	29.70
Physical	13	5.94	97.19	52.91	30.41

On the SIS instrument there was one question that captured the perception of caregivers on the percentage of stroke recovery by the post-stroke individual. The mean score for this question was 56.15 (SD = 25.10) that indicated caregivers felt post-stroke individuals achieved around 50% recovery to a pre-stroke state.

Profile of Mood States (POMS)

The short version of POMS that was employed in this study consisted of 35 items with 5-point interval scales to capture the caregiver's self-report on his or her feeling and affective states. There were seven dimensions of mood captured on the POMS that included (Heuchert & McNair, 2012): tension, depression, anger, vigor, fatigue, friendliness, and confusion. Caregivers were asked to read the list of words that described the feelings and emotions that they had experienced over the week prior to completing the study questionnaires. Caregivers' responses were scored from 0 (Not at all) to 4 (Extremely) units (Table 4.4). Among these seven dimensions, only six of them were involved in the Total Mood Disturbance Score. Friendliness

was a separate item in the POMS. Summing the subscales produced a Total Mood Disturbance (TMD) Score = Anger-Hostility (AH) + Confusion-Bewilderment (CB)+ Depression-Dejection (DD) + Fatigue-Inertia (FI) + Tension-Anxiety (TA) minus Vigor-Activity (VA)). The theoretical range of TMD scores can be minus 25 to plus 100. In the current study, the mean score of the TMD Score was 18.23 (SD = 22.89, range = 12.53 to 53.00). Higher scores indicated greater mood disturbances or more negative mood states in caregivers. Among all the six mood states, each mood state was represented by 5 items ranging from 0 (did not feel the specific mood state at all) to 20 (highly/extremely experience of the specific mood state). The fatigue-hostility had a highest mean score (M = 9.92, SD = 7.44), which indicated caregivers felt more fatigue compared to other mood states in the caregiving process. Caregivers' fatigue-hostility mood state was followed by vigor (M = 9.62, SD = 4.07), tension (M = 5.54, SD = 4.52), confusion (M = 4.31, SD = 3.88), anger (M = 4.15, SD = 4.02), and depression (M = 3.92, SD = 3.80).

Table 4.4 Descriptive Statistics of Caregiver Self-Reports on Mood States

	N	Minimum Score	Maximum Score	Mean Score	Std. Deviation
Anger	13	0	13	4.15	4.02
Tension	13	0	13	5.54	4.52
Confusion	13	0	13	4.31	3.88
Vigor	13	3	15	9.62	4.07
Depression	13	0	12	3.92	3.80
Fatigue	13	0	19	9.92	7.44
Friendliness	13	6	20	14.08	3.71

Of note, Friendliness was regarded as a separate mood-related item in the POMS instrument. Friendliness is a mood-related state that may alter the severity of mood disturbance reflected in the interpersonal functioning domain (Heuchert & McNair, 2012). In the POMS,

friendliness is different from the other mood states because it is distinctly interpersonal in nature. The theoretical range for the Friendliness item was 0 to 20. In this study, the mean score of friendliness was 14.08 (SD = 3.71) indicating that caregivers felt a positive interaction with post-stroke individuals. The higher the number meant the more prevalence of positive mood states.

Empathic Responding Scale (ESR)

The Empathic Responding Scale was employed to capture caregiver self-reports on their empathy-related responses toward post-stroke patients in this study. Across the 10-scaled items on the Empathic Responding Scale, the mean of total score was 3.42 (SD = 0.59) (Table 4.5). Of the theoretical range of zero and four on the scale, the total mean score of 3.42 indicated caregivers perceived themselves as engaging in a moderate level of empathic behaviours. In addition, the highest mean item scores were on the individual items, “ I try to help the patient by doing something for him/her”(M = 3.69, SD = 0.48). The lowest mean item scores were for the item, “I try to experience what the patient is feeling” (M = 3.00, SD = 1.00).

Table 4.5 Descriptive Statistics of Caregiver Self-Reports on Empathic Responding

	Total Sample	Minimum- Maximum Score	Mean Score	Std. Deviation
1. I try to understand the patient's concerns.	13	2-4	3.38	0.77
2. I try to understand how the patient felt.	13	2-4	3.38	0.77
3. I try to experience what the patient is feeling.	13	1-4	3.00	1.00
4. I try to imagine myself in the patient's shoes.	13	1-4	3.08	1.04
5. I try to see things from the patient's point of view.	13	2-4	3.31	0.86
6. I try to accept the patient as he or she is now.	13	2-4	3.54	0.78
7. I try to help the patient by listening to him or her.	13	3-4	3.62	0.51
8. I try to help the patient by doing something for him or her.	13	3-4	3.69	0.48
9. I try to figure out what would make the patient feel better.	13	2-4	3.62	0.77
10. I try to comfort the patient by telling him or her about my positive feelings for him or her.	13	1-4	3.54	0.88
Empathic Responding Scale Mean Total Score	13	2.20-4.00	3.42	0.59

Analysis of the Research Questions

In order to answer research questions #1 to 3, Spearman's correlation *rhos* were conducted between ordinal-level variables (see Table 4.5-4.7). The researcher explored the existence of significant associations ($p < 0.05$) and non-significant trends ($p < 0.1$) in associations between study variables in this small study sample. The strength of the relationships was based on the following criteria by Hazard Munro (2005): when the correlation coefficient is 0.00 to 0.25, it means a little, or if any relationship exists between two variables; when the correlation coefficient is 0.26 to 0.49, it means a low relationship exists between two variables; when the correlation coefficient is 0.50 to 0.69, it means a moderate relationship exists between two variables; when the correlation coefficient is 0.70 to 0.89, it means a high relationship exists between two variables; and, when the correlation coefficient is 0.90 to 1.00, it means a very high relationship exists between two variables.

Research Question #1: What is the relationship between the patient's functional deficits and the caregiver's emotional or psychological states?

The Spearman's correlation test was conducted to examine the relationship between caregivers' perceptions of patients' functional deficits and caregivers' emotional or psychological states (Table 4.6). The Stroke Impact Scale (SIS) (proxy version) was used to measure caregivers' perceptions of the impact of stroke on patients' functional status in relation to their perception of post-stroke individuals' physical, emotion, communication, memory, and social function deficits. The Profile of Mood States (POMS) was used to evaluate caregivers' emotion or psychological states, which were Total Mood Disturbance Score based on six mood states of anger, depression, fatigue, tension, confusion, and vigor.

Table 4.6 Correlations (Spearman's rho) Between Caregivers' Perception of Patients' Functional Deficits and the Caregiver's Emotional States

		Caregivers' Emotional States (b)						
		Anger rho (2- tailed)	Tension rho (2- tailed)	Confusion rho (2- tailed)	Vigor rho (2- tailed)	Depression rho (2-tailed)	Fatigue rho (2- tailed)	TMD rho (2- tailed)
Caregivers , Perception of Patients' Functional Deficits (a)	Emotion							
	<i>rho</i> (2-tailed)	-.539 .057	-.508 .077	-.565* .044	.483 .044	-.506 .077	-.829** .000	-.666* .013
	Memory							
	<i>rho</i> (2-tailed)	-.269 .374	-.161 .599	-.194 .526	.311 .321	-.285 .346	-.299 .322	-.238 .434
	Communi cation							
	<i>rho</i> (2-tailed)	-.787** .001	-.563* .045	-.744** .004	.721* .005	-.835** .000	-.636* .019	- .890* .000
	Social Participa- tion							
	<i>rho</i> (2-tailed)	-.173 .571	-.344 .250	-.326 .276	.322 .283	-.210 .490	-.621* .024	-.299 .321
	Physical							
	<i>rho</i> (2-tailed)	-.263 .385	-.378 .203	-.262 .387	.030 .921	-.142 .643	-.302 .316	-.184 .547

Note: *rho* indicates correlation coefficient; 2-tailed test indicates p-value (significance level).

- 0 to 100 units; lower scores indicated higher negative impact on patients' health-related quality of life.
- 0 to 4 units; higher scores indicated more of each mood state for caregivers.

Results from conducting Spearman's correlation test confirmed that there was a moderate negative correlation between patient emotional status and caregivers' emotion ($\rho = -0.67$, $p = 0.01$). In other words, when caregivers thought that the post-stroke individual was experiencing more negative emotions (as reflected in their low score on the emotion domain), caregivers also experienced more negative emotions toward the patient (as reflected in their higher score on the TMD variable). In addition, there was a strong negative correlation between caregivers' perception of post-stroke individuals' emotional status and caregivers' fatigue ($\rho = -0.83$, $p < 0.001$). In fact, when caregivers perceived the post-stroke individual was experiencing negative emotions, caregivers would experience more fatigue during the caregiving process.

Supplemental analyses were conducted to offer potential insights on associations between caregiver perceptions of patients' communication function and caregiver mood state sub-scale responses (anger, tension, confusion, depression, fatigue and vigor) on the POMS. There were several moderate to strong negative associations between patients' communication function deficits and six mood states of caregivers. First, there was a strong negative association between caregiver perception of patients' communication function and caregiver depression ($\rho = -0.84$, $p < 0.001$) (reflected as a higher score for 'depression' as captured on the POMS). In other words, the more caregivers noted patient's reduced communication ability, the more caregivers felt depressed. Other negative significant associations involved caregiver perceptions of patients' communication ability and caregiver anger ($\rho = -0.79$, $p = 0.001$). In other words, the more caregivers noted patients' reduced communication ability, the more caregivers experienced anger. Lastly, there was a strong negative association between caregiver perception of patients' communication capability and caregiver confusion ($\rho = -0.74$, $p = 0.004$). In other words, the more caregivers noted patients' reduced communication capability, the more caregivers felt

confused or puzzled (reflected as a higher score for ‘confusion’ as captured on the POMS).

Beside caregiver perception of post-stroke individual’s communication deficits, there was moderate negative relationship between caregiver perception of social participation functional impairment and caregiver fatigue. In other words, the more caregivers noticed patients’ reduced social participation ability, the more caregivers felt fatigue.

In addition, there was a strong negative relationship between caregiver perception of patients’ communication functional status and caregiver emotional states (reflected in their TMD score: $\rho = -0.89$, $p < 0.001$). In other words, the more caregivers perceived that patient communication status was negatively affected by stroke, the more they reported experiencing negative emotions (i.e., as reflected in the higher score of the TMD variable).

In terms of other sub-scale domains captured in the SIS, there were no significant relationships found between how caregivers perceived patients’ physical functional deficits, memory function, and caregivers’ emotional status.

Research Question #2: What is the relationship between the caregiver’s emotional or psychological states and the caregiver’s empathy-related helping behaviour?

To answer this question, Spearman’s correlation tests were conducted to examine the relationship between caregiver emotional or psychological states and caregiver empathy-related helping behaviour (Table 4.7). As for Research Question #1, the Profile of Mood States (POMS) tool was used to evaluate caregivers’ emotional or psychological states, which included six mood states: anger, depression, fatigue, tension, confusion, and vigor. The total Empathic Responding Scale (ESR) was used to investigate caregiver empathy-related helping behaviour in relation to caregiver emotional or psychological states. The findings revealed that there was no relationship

between caregivers' total mood state score (Total Mood Disturbance Score) and caregivers' empathy-related helping behaviours (ρ of 0.16 for $p = 0.61$).

The researcher also examined more closely the potential relationships between sub-scale items captured on the POMS (anger, tension, confusion, depression, fatigue, and vigor) and caregivers' empathy-related helping behaviours. One significant finding indicated that there was a moderate negative correlation between caregiver fatigue and caregiver empathy-related helping behaviour ($\rho = -0.59$, $p = 0.036$). In other words, when caregivers felt more fatigued (i.e., as reflected in their higher score on fatigue), caregivers engaged in less empathy-related helping behaviour toward patients. There were no other relationships found between caregiver POMS sub-scale items (anger, tension, confusion, depression, or vigor) and caregiver empathy-related helping responses.

Table 4.7 Correlations (Spearman's ρ) Between the Caregiver's Emotional or Psychological States and the Caregiver's Empathy-related Helping Behaviour

		Caregiver's Emotional States (b)						
		Anger ρ (2- tailed)	Tension ρ (2- tailed)	Confusion ρ (2-tailed)	Vigor ρ (2- tailed)	Depression ρ (2-tailed)	Fatigue ρ (2- tailed)	TMD ρ (2- tailed)
Caregiver's Empathy- related Helping Behaviour (a)	ERS							
	ρ (2- tailed)	-.081	.131	-.006	.221	-.034	-.586*	-.157
		.791	.669	.986	.468	.913	.036	.607

Note: ρ indicates correlation coefficient; 2-tailed indicates p-value (significance level).

- 0 to 4 units; higher scores indicated more involvement to empathy-related helping behaviour.
- 0 to 4 units; higher scores indicated more of each mood state for caregivers.

Research Question #3: What is the relationship between the patient's functional deficits and the caregiver's empathy-related helping behaviour?

To answer this research question, Spearman's correlation tests were conducted to investigate relationships between caregiver perceptions of patient functional deficits and caregiver empathy-related helping behaviours (Table 4.8). As for Research Question #1, the Stroke Impact Scale (SIS) (proxy version) was used to measure caregivers' perceptions of patients' physical, emotion, communication, memory, and social participation impact after stroke. The total Empathic Responding Scale (ERS) was used to investigate caregiver empathy-related helping behaviour in relation to caregiver responses on the SIS and SIS sub-scales.

Table 4.8 Correlations (Spearman's rho) Between Caregivers' Perception of Patients' Functional Deficits and the Caregiver's Empathy-related Helping Behaviour

		Caregivers' Perception of Patients' Functional Deficits (b)				
		Emotion rho (2-tailed)	Memory rho (2-tailed)	Communication rho (2-tailed)	Social Participation rho (2-tailed)	Physical rho (2-tailed)
Caregiver's Empathy- related Helping Behaviour (a)	ERS rho (2-tailed)	.338 .259	.073 .813	.113 .712	.472 .103	.163 .595

Note: *rho* indicates correlation coefficient; 2-tailed indicates p-value (significance level).

- 0 to 4 units; higher scores indicated more involvement to empathy-related helping behaviour.
- 0 to 100 units; lower scores indicated higher negative impact on patients' health-related quality of life.

There were no significant relationships between the caregivers' perception of patient functional status and caregiver empathic response towards patient. These findings suggested that the caregivers' perception of patient functional status was not directly related to caregiver empathic responses toward post-stroke individuals.

Research Question #4: Are the patient's functional deficits and the caregiver's psychological or emotional states predictive of the caregiver's empathy-related helping behaviour?

A series of regression analyses were initially planned to determine which variables might serve as potential predictors of caregiver empathy-related helping behaviour. However, due to the small sample size, regression analyses could not be done. (B. Dufault, statistician, personal communication, March 14, 2013). As well, according to bivariate correlational analysis, only caregiver fatigue was significantly associated with caregiver empathy-related helping behaviours.

Summary

This purpose of this study was to identify and assess relationships among functional deficits of individuals dealing with post-stroke (according to the perception of the caregiver), the family caregiver's emotions (psychological distress), and the family caregivers' ability to empathize with post-stroke individuals. Analyses and interpretation of data collected from 13 caregivers of post-stroke individuals were conducted in this study. Descriptive analysis of the data allowed the researcher to describe the typical characteristics of participants in this study. The average age of caregiver participants was 59 years of age, which was older than post-stroke individuals in the study. The majority of caregivers spoke English, were female, and the majority were the post-stroke individuals' spouse. Acceptable internal consistency reliability estimates

were reported for the SIS, POMS, and ERS when employed with caregivers of post-stroke individuals in this study. Caregivers' perceptions of the post-stroke individuals' function deficits, their own emotional states, and their own empathy-related helping behaviour toward post-stroke individuals were analyzed using descriptive statistics. Spearman's correlational statistics were employed to examine relationships between family caregivers' responses on the Stroke Impact Scale, the Profile of Mood States, and the Empathic Responding Scale.

Regarding a descriptive summary of the patient's functional status according to the perspective of the caregiver, the communication domain had the highest mean score. In other words, caregivers perceived patients' communication ability had been affected the least after having experienced a stroke. Caregivers reported that the physical function status of patients was affected the most by stroke. Regarding caregivers' emotional or psychological emotional states, as captured in the POMS, caregivers reported a high level of fatigue in the context of caring for post-stroke individuals. Caregivers also reported that their experience with depression was the lowest in comparison to their reports on the other emotional or psychological states of anger, tension, confusion, fatigue and vigor. In this study's sample of family caregivers, the findings indicated that they perceived themselves as engaging in a moderate level of empathic behaviour toward the patient.

Inferential analysis of data yielded a number of important findings in relation to the respective research questions. In an attempt to determine relationships among caregiver perceptions of patients' functional deficits, caregiver emotional and psychological states, and caregiver empathy-related helping behaviours toward an individual who was dealing with post-stroke, a series of Spearman's correlation analyses were employed.

For Research Question #1 that examined the relationship between caregiver perceptions of patients' functional status and caregiver emotional or psychological states, a number of significant findings were revealed. For instance, when caregivers perceived that patients were affected negatively in their emotions after stroke, (i.e., as reflected in their low score on the emotion domain), caregivers reported that they also experienced a higher level of negative emotions (i.e., as reflected in their high negative emotion score on the TMD). In the researcher's supplemental analyses, the results illustrated that the more caregivers perceived the post-stroke individual was experiencing negative emotions, the more caregivers would feel fatigue. The results further showed that the more caregivers perceived the post-stroke patient was experiencing poor communication abilities as a result of stroke, the more they reported feeling more depression and anger. The researcher also found that the more caregivers perceived the patient as being influenced negatively in their emotions as a result of stroke, the more they reported feeling puzzled or confused (i.e., as reflected in their higher score on the 'confusion' sub-scale in POMS) during the caregiving.

For Research Question #2, in determining the relationship between caregiver emotion (Total Mood Disturbance (TMD) score) and caregiver empathy-related helping behaviour, no significant relationship was found. However, in investigating relationships between sub-scale scores on the POMS with caregiver responses on the ERS, there was one highly significant negative correlation found between caregiver fatigue and caregiver empathy-related helping behaviour toward the patient. In other words, the more caregivers reported feeling fatigued, the less they engaged in empathy-related helping behaviours toward the patient.

For Research Question #3, there were no significant findings that indicated associations between how the caregiver perceived the impact of stroke on patient physical, emotional,

memory function, communication ability, and social participation ability, and caregiver empathic responses to the patient.

CHAPTER FIVE: DISCUSSION

Introduction

This pilot study set out to examine associations among caregiver perceptions of post-stroke individual functional deficits, caregiver emotional or psychological states, and caregiver empathy-related helping behaviours toward post-stroke individuals. This study's findings serve to enhance a preliminary understanding about the caregiving process and caregiver experiences in the context of post-stroke care. These findings also provide insights for rehabilitation professionals who are interested in enhancing post-stroke care in the community and offering evidence-informed supports to family caregivers. However, due to the limited number of family caregivers who participated in this study ($n = 13$), a caveat is warranted in interpreting the generalizability of this pilot study's findings to the wider population of post-stroke individuals and their family caregivers. The information gathered from this study should be considered a preliminary foundation upon which to build further knowledge of family caregivers' experiences in their care of post-stroke individuals in a larger study.

Overall, the study was guided by the concepts of patient functional deficits, caregiver emotional status, and caregiver empathy-related helping behaviours according to the perspective of the family caregiver. Davis's (1994) organizational model of empathy provided the foundation for conceptualizing respective relationships among post-stroke individual functional deficits, caregiver emotional states, and caregiver empathic helping behaviours toward the post-stroke individual.

As guided by Davis's (1994) empathy model, the family caregiver can be a witness to the suffering or distress of a patient dealing with post-stroke. Depending on the strength of the

situation experienced by the patient (Davis, 1994), different intrapersonal responses, such as empathic processes in the family caregiver might be evoked in response to witnessing the distress or suffering of the patient. In this study, functional deficits experienced by patients with stroke represented one type of situation variable that could have a direct relationship to caregiver empathic responses toward post-stroke individuals (addressed in Research Question #2). The second strength of the situation variable in this study was represented by caregiver emotional or psychological status (e.g. caregiver anger) that could also be directly related to the empathic response by the family caregiver toward the post-stroke individual (addressed in Research Question #3).

Of note, Research Question #4, “Are the patient’s functional deficits and the caregiver’s psychological or emotional states predictive of the caregiver’s empathy-related helping behaviour?” was not analyzed. A regression analysis was initially planned to determine which variables might serve as potential predictors of caregivers’ empathy-related helping behaviours toward post-stroke individuals. However, due to the small sample size, the regression analysis was not performed (B. Dufault, Statistician, personal communication, March 14, 2013).

A discussion of results for Research Questions #1 to #3 will follow, including a comparison of this study’s results with findings described in related literature. Following a discussion of this study’s limitations, clinical practice implications and recommendations for future research are described.

Discussion of Descriptive Findings

Representativeness of this Study’s Sample

The majority of caregivers in this study’s sample were female, spouses to the affected

individual, and had been taking care of the post-stroke patient for over 24 months. The average age of caregivers was 59.15 years, slightly older than post-stroke patients ($M = 58.15$ years). According to previous reports, stroke occurs predominantly in people aged 65 years and older (Lezak, 2004). Family caregivers in this study also appeared to be a reasonable representation of caregivers of post stroke individuals. The large proportion of female caregivers in this study who were spouses of affected individuals was consistent with the composition of caregivers described in the stroke caregiver literature (Anderson et al., 1995; Dennis et al., 1998; van den Heuvel, 2001). Most caregivers in this study's small sample identified English as the primary language that was spoken at home. Therefore, it is difficult to generalize findings from this study to different ethnic groups of individuals dealing with stroke in the home care setting.

Representativeness of Patient Functional Deficits, Caregiver Emotions, and Caregiver Empathic Responses

Functional Deficits. Family caregivers provided their perceptions of the affected individual's functional deficits following stroke that were captured on the Stroke Impact Scale (SIS) (Duncan, Lai, & Perera, 2002). In the SIS there were five domains representing the quality of life of post-stroke individuals. According to previous literature, post-stroke patients can experience an array of sensorimotor impairments. For instance, physical disability and daily functioning complications are possible after experiencing a stroke (National Stroke Foundation, 2005; Warlow et al., 2003). In the current study, post-stroke individuals' physical functioning was most affected by stroke that was followed by deficits in emotion, social role, and memory functions. The least affected functional status domain was the communication ability of patients who were affected by stroke, as perceived by their family caregivers.

To compare functional deficits experienced by patients affected by stroke as perceived by their caregivers in this study with other studies, the researcher reviewed the stroke literature. Aphasia is a common impairment following stroke and is characterized by difficulties in language and communication, including auditory comprehension and the formulation of grammatical verbal messages (e.g. verbal fluency and naming) (Mukherjee, Levin & Heller, 2006). In the current study, caregivers reported that affected individuals' communication capabilities were least affected by stroke. This finding suggests that caregivers who agreed to participate in this study were likely those who were able to engage in empathic dialogue with patients whose communication abilities were not severely influenced by stroke. Other cognitive deficits following stroke can include difficulties with attention, memory (Madureira, Guerreiro & Ferro, 2001; Teasdale & Engberg, 2005) and executive (frontal lobe) functioning (Mukherjee et al., 2006). Memory functioning deficits in patients were also reported by caregivers in this study. The most widely researched and commonly reported emotional difficulties are depressive symptoms (Dennis et al., 1998; Mackenzie et al., 2007; Hackett, Yapa, Parag, & Anderson, 2005; Young, Murray, & Forster, 2003) in post stroke patients. Anxiety and related emotional responses such as insecurity and distrust could also occur following a stroke, and often co-exist with depression (Hochstenbach & Mulder, 1999; Mineka, Watson, & Clark, 1998). Other emotional problems can include general emotional lability that is characterized by outbursts of anger and irritability (Mukherjee, Levin, & Heller, 2006; Teasdale & Engberg, 2005) or feelings of resentment towards other people or for the stroke occurring (Clarke & Black, 2005; Hochstenbach & Mulder, 1999). In addition, other researchers have described that post-stroke patients participated in fewer recreation or leisure, social, and family activities following their stroke (Hommel et al., 2009; Teasdale & Engberg, 2005; Young, Murray, & Forster, 2003). In

the current study, stroke also appeared to have an impact on affected individuals' emotional functioning and their social participation functioning, according to reports by the family caregiver.

Overall, the quality of life domain findings as captured in the current study coincided with other research studies. Based on mean scores reflecting caregivers' perceptions of affected individuals' functional deficits in four quality of life domains, the domain that was affected most by stroke was physical function, followed by social participation ability, emotional function, memory function and communication function. Despite the small sample size of this study, this study's findings reflect results captured in other studies that examined the quality of life domains of patients affected by stroke.

Caregiver Emotions. In this study, the Profile of Mood States (Heuchert & McNair, 2012) tool was employed to measure caregivers' self-reports on six mood states: anger, tension, confusion, depression, fatigue, and vigor, in order to assess the Total Mood Disturbance score. Caregivers who participated in this study reported more fatigue than other psychological states captured in the POMS, such as vigor that was then followed by caregiver reports of tension/anxiety, confusion, anger, and depression. Regardless of the condition, disability, or illness that affected individuals might be dealing with, the caregiving literature described that caregivers experience different types and levels of distress associated with the caregiving role (Simon, Kumar & Kendrick, 2009). Studies have consistently demonstrated that family caregivers are at risk for developing depression, anxiety, sleep disturbances, poor quality of life, and health problems (Berg, Palomaki, Lonnqvist, Leththialmes, & Kaste, 2005; Saban, Sherwood, Paula, DeVon, & Hynes, 2010; Schlote, Richter, Frank, & Wallesch, 2006; Ski & O'Connell, 2007; van Exel, Koopmanschap, van den Brouwer, & van den Bos, 2005). The

reports of emotions from caregivers in this study are supported by general stroke caregiving literature where caregiver fatigue, vigor, and anxiety are highly prevalent emotions for stroke caregivers.

Although caregivers in this study reported fatigue as being the most troublesome mood state, they also reported moderate levels of vigor. This level of vigor was reported by caregivers in this study might be partially explained by related findings of other investigators who demonstrated the benefit of caring for someone with a medical illness in general (Brouwer, Van Exel, Van Den Berg, Van Den Bos, & Koopmanscap, 2005), and more specifically with stroke (Johnson, 1998). Experiencing positive outcomes and enjoyment from the process of caregiving could be influenced by individuals' appraisal of the caregiving situation, as well as the amount of objective burden, i.e. the number of hours spent caregiving (Hilgeman, Allen, DeCoster & Burgio, 2007). Unfortunately, the researcher in the current study did not capture a direct appraisal of the caregiving situation by family caregivers, which warrants further study. Of note, this researcher did not find a significant correlation between perceptions of caregivers on patient functional deficits, such as physical functioning and caregiver vigor, which was likely due to challenges in uncovering significant associations in this small study sample.

Caregiver Empathic Responses. The Empathic Responding Scale (ERS) (O'Brien & Delongis, 1990) was used to capture the caregiver's self-report of empathy-related helping responses toward the affected individual. In the current study, caregivers perceived themselves as engaging in empathy-related helping behaviours toward the individual who was dealing with post-stroke. For instance, the highest mean item score reported by caregivers was on the item, "I try to help the patient by doing something for him/her" ($M = 3.69$). The lowest mean item score on "I try to experience what the patient is feeling" ($M = 3.00$). Across individual items in the

ERS, the mean scores ranged from 3 to 3.69 units for caregivers. Overall these findings on individual ERS items suggested that caregivers felt engaged in a moderate to high amount of empathy-related helping behaviours with the patients. The mean total ERS score (based on an average score across ERS items) was 3.42 units in this study. The researcher compared the mean total ERS score obtained in the current study with the total ERS scores reported in related studies. In Hansen's (2009) study of 33 patients- caregivers dyads where patients were diagnosed with COPD, lung cancer, or colorectal cancer, family caregivers in the smoking-related illness group perceived their own empathic behaviour total summed score across ERS items was 35.32, and family caregivers of colorectal cancer patients perceived empathic behaviour total score was 36.87. These results are difficult to compare with results obtained in the current study as Hansen (2009) provided a summed score for the ERS scale, whereas the researcher reported on an average total ERS score. In Bokhari's (2006) study of 13 women with stages I to IV ovarian cancer where the majority patients were diagnosed with disease recurrence, the average score of the ERS score was 2.86 (SD = 0.90) (Bokhari, 2006), which was slightly lower than the average total ERS score which was 3.42 (SD = 0.59) in the current study. Of note, Bokhari's (2006) results are based on responses by patients with ovarian cancer on their caregiver's empathic responses captured on the ERS tool: whereas in the current study, caregivers provided self-reports on their empathic responses toward the patient dealing with stroke.

Discussion of Results for Research Questions #1 to #3

Research Question #1: What is the relationship between the patient's functional deficits and the caregiver's emotional or psychological states?

Analysis of pilot data for Research Question #1 revealed that there was a moderate negative correlation between the post-stroke individual's deficits in his or her emotional state and the caregiver's emotion state (the total score of POMS). This finding indicated that when caregivers perceived a poor emotional status in post-stroke individuals, they would experience more negative emotions themselves. In the supplementary analysis, there was a strong negative correlation between caregivers' perception of post-stroke individuals' emotional status and caregivers' fatigue. In other words, when caregivers perceived that the post-stroke individual was experiencing negative emotions, caregivers would experience more fatigue during the caregiving process.

In a related study with 399 post-stroke individuals and their caregivers by Cameron et al. (2011), caregivers reported more emotional distress when they were caring for post-stroke individuals who exhibited more depressive symptoms and were experiencing more cognitive impairment. Findings from this study and related studies suggested that caregivers of post-stroke individuals with poor emotional states were likely to experience poor emotional outcomes themselves (Dennis et al., 1998; Perrin, Heesacker, Hinojosa, Uthe, & Rittman, 2008).

Second, the researcher found a significant negative correlation between caregiver perception of communication deficits in care recipients and caregiver total mood states. This finding indicated that the more that communication deficits existed in post-stroke individuals, the more caregivers would experience overall psychological distress or negative mood states as captured on the total POMS scale. In Draper's study (2007), spouses who were caring for post-

stroke individuals whose speech was affected by the stroke were more likely to experience strain than those post-stroke individuals whose speech was not affected by stroke. For caregivers and individuals affected by stroke, optimal communication can be challenging due to the consequences of stroke. If the post-stroke individual's communication abilities are affected, these affected individuals and their caregivers are not able to effectively discuss their respective ideas, feelings, and concerns (Draper, 2007). The result of sub-optimal communication patterns by patients can be misunderstanding, confusion, and a poor evaluation of thoughts, feelings, behaviours, and goals for care by caregivers and post-stroke individuals. This study's findings, as supported by related study findings, suggested that caregivers' emotional status is negatively linked to communication deficits experienced by individuals with stroke.

Supplemental analyses also revealed several significant negative associations between caregiver perceptions of post-stroke individual communication deficits and caregiver depression, anger, anxiety, confusion and fatigue (sub-scales on the POMS tool). In other words, when caregivers perceived more communication deficits in post stroke individuals, they would feel more depression, anger, anxiety, confusion, and fatigue. Communication difficulties due to aphasia following the stroke can be particularly stressful to caregivers (Michallet, Le Dorze, & Tetreault, 2001). Most studies concluded that caregivers of aphasic stroke patients were more stressed, with more symptoms of depression, loneliness and other emotional problems than caregivers of non-aphasic stroke patients (Rombough, Howse, & Bartfay, 2006). The loss or impairment of the ability to communicate was typically devastating and frustrating to both post-stroke individuals and their primary caregivers, and could result in fear, feelings of hopelessness, and depression in the caregiver (Hickey, 2001). This study's findings on linkages between patient deficits in communication ability and caregiver mood states make an important

contribution to an area where there has been little known about the effects of aphasia on the post-stroke individual and his or her family caregiver in the home environment.

Third, apart from the affected individual's communication deficits and social participation impairments following stroke, there were no significant associations found between caregiver perceptions of post-stroke patients' physical, memory, and caregiver psychological status. In a related study, Cameron et al. (2011) also found that post-stroke individuals' physical disability, stroke severity, and comorbidity were not significantly associated with caregiver distress. However, in an earlier study by Cameron, Cheung, Streiner, Coyte, and Stewart, (2006), caregivers were found to experience more depressive symptoms when they cared for post-stroke individuals who exhibited more memory, comprehension, and psychological symptoms. Again, due to the small sample size of this study, the lack of significant results between patient physical, memory, and social deficits, and caregiver psychological status are not conclusive.

In summary, caregivers of stroke patients in this study often had to cope with patients' physical, cognitive impairment, communication, behavioural changes, and emotional problems. Communication deficits experienced by individuals affected by stroke (based on the caregiver's perceptions) appeared to have a direct linkage with caregivers' negative emotions such as depression, anger, and confusion which has received limited attention in the caregiver stroke care literature to date.

Research Question #2: What is the relationship between the caregiver's emotional or psychological states and the caregiver's empathy-related helping behaviour?

The researcher's analysis of data for Research Question #2 was an attempt to provide evidence in support of the theoretical linkage between the caregiver's emotional state (a situation variable) and the caregiver's empathy-related helping behaviour (an intrapersonal outcome)

toward the patient as postulated in Davis's (1994) Empathy Organization Model. There were six caregiver emotional states included in the calculation of Total of Mood Disturbance score in this pilot study by the POMS tool: five were negative emotions: anxiety, anger, depression, fatigue, and confusion. Vigor was the only positive emotion involved in the calculation of Total Mood Disturbance score. Of the six individual mood states captured in the POMS sub-scales, only caregiver fatigue was moderately correlated with caregivers' empathic helping behaviours. This finding indicated that when caregivers were more fatigued, they engaged in less empathy-related helping behaviours toward the affected individual dealing with stroke. Family caregivers are key in providing safe care to a growing number of individuals dealing with chronic and serious illnesses, or disabled older adults living in the community (MacNeil, Robin, & Schmidt, 2009). Unfortunately, many of these caregivers experience considerable stress and are at higher risk for poorer mental and physical well-being than non-caregivers (Bookwala, Yee, & Schulz, 2000). Diminished mental and physical well-being of caregivers who provide care on a long-term basis can contribute to caregiver fatigue. In turn, caregiver fatigue can negatively affect caregivers' ability to provide supportive, empathy-related helping behaviour to post-stroke individuals. According to Davis (1994), engagement in empathic processes is an effortful mental exercise. Findings in this study suggested that caregiver fatigue is a 'situation factor' that can have a negative linkage with the caregiver's motivation to engage in a cognitive activity that requires considerable energy, such as empathy-related helping responses toward the post-stroke patient.

In the current study there were no associations found between caregiver empathy-related responses, and other caregivers' emotion states, except for fatigue. These findings are not consistent with other study findings. For example, in McNeil et al.'s (2010) study that was conducted with 417 caregivers of older care recipients, the findings revealed that the degree to

which caregivers experienced anger had an influence on the quality of care provided by caregivers. Although McNeil et al. (2010) did not examine relationships between caregiver emotions and empathy-related helping behaviours, they did report that caregiver anger predicted potentially harmful behaviours toward care recipients. Depressed caregivers were more likely than non-depressed caregivers to be subjects of investigation by social service agencies for possible elder mistreatment (Bonnie & Wallace, 2003; Wolf, 1996). As well, feelings of resentment of family caregivers were associated with potentially harmful behaviours toward care recipients (Beach et al. 2005; Williamson et al., 2001). Conversely, care described as high in quality in relation to empathic sensitive responses toward the affected individuals by caregivers and/or their care recipients was more common among caregivers who expressed fewer depressive symptoms (Dooley, Shaffer, Lance, & Williamson, 2007). Indeed, it can be reasonably assumed that when caregivers experience fewer negative psychological states they would likely exhibit or engage in more sensitive, empathy-related behaviours toward the affected individual. Other than caregiver fatigue, this study did not find support for associations between negative emotional states by caregivers and their empathy-related behaviours that warrant further investigation in a larger study.

To recap, caregiver fatigue was significantly associated with caregiver empathy-related helping behaviours toward post-stroke individuals. In other words, when caregivers are fatigued it is likely that they are less motivated to exert mental energy to comprehend the patient's needs from the viewpoint of the patient. Based on the analysis in Question #1, there was also a strong negative correlation between caregivers' perception of post-stroke individuals' emotional status and caregivers' fatigue. According to these two associations, a larger study is warranted that examines the potential mediating linkage by caregiver fatigue on the association between

caregiver perception of negative emotions by patients and their empathic responses toward the patient. In other words, when the caregiver sensed that the post-stroke individual was having negative emotions, he or she would experience more fatigue which in turn had a negative influence on their empathic responses toward the patient.

Non-significant relationships involving caregiver depression, anger, tension, and confusion (as captured by the POMS tool) and empathy-related helping behaviours by caregivers were found. These study findings are inconsistent with other study findings (e.g., Lee, Brennan, & Daly, 2001) where caregivers with high empathy reported that their caregiving situation was less stressful and that they were less depressed and more satisfied with life in comparison to caregivers with low empathy (Borg & Hallberg, 2006). Again, due to the small sample size of this study it was difficult to detect the existence of significant linkages between caregiver empathy-related behaviours and caregiver mood or emotional states that have been captured in related studies.

Research Question #3: What is the relationship between the patient's functional deficits and the caregiver's empathy-related helping behaviours?

The analysis of data for Research Question #3 examined the potential relationship between patient functional deficits (a situation factor) and caregiver empathy-related helping behaviours (an intrapersonal outcome) as postulated in Davis's (1994) Empathy Organizational Model. Caring for people with stroke can be difficult and stressful due to the post stroke individual's sensory, motor, visual, cognitive and emotional problems, and deficits in communication abilities (Bakas, Austin, Jessup, Williams, & Oberst, 2004). In this study, the Stroke Impact Scale (SIS) was used to measure caregiver perception of post-stroke individual physical, emotional, communication, memory, and social participation functional deficits.

However, in this study there were no relationships found between caregiver perceptions of post stroke individual functional deficits and caregiver empathy-related helping behaviours. In a related study reported by Lobchuk et al. (2008), patients with end-stage ovarian cancer stated that their caregivers' empathic behaviour helped in decreasing their levels of depression and anxiety in dealing with the disease. Of note, in this study, the researcher did not measure the patient's self-report of stroke impact deficits and emotional status in relation to the patient's perception of the caregiver's empathic behaviours toward patients.

The current study is limited in not having taken a dyadic approach in capturing both partners' viewpoints of the linkage between patient functional deficits and caregiver empathy-related behaviours. Overall, it is difficult to comprehend why there was no linkage found between patient functional deficits from the caregiver's viewpoint and caregivers' empathic responses: that is, apart from the small size of this study's sample that made it difficult to detect significant linkages between study variables. According to Davis (1994) and Batson et al. (1997), it is postulated that when people see someone suffering they are likely to experience some degree of personal distress that leads to altruistic helping behaviours. In other words, when people feel connected to the person suffering, it facilitates helping behaviours in the person who witnesses another person's suffering. Another plausible explanation for the lack of association between patient functional deficits and caregiver empathy-related helping is that the patient's functional deficits were not remarkable enough (i.e., the mean scores for all domains were above 50 indicating less stroke impact on the functional domain). In other words, post-stroke individuals' functional deficits, according to caregivers in this study, were not severe enough to serve as a strong motivating factor for caregivers to engage in the effortful activity of empathy. As well, the researcher examined the responses of caregivers to individual items on the Empathic Responding

Scale. It was discovered that caregivers reported lower scores for engaging in attempts to comprehend the patient's perspective in comparison to other items on the tool (i.e., items that did not address the caregiver's motivation or attempts to engage in the patients viewpoint; for example, "I try to help the patient by doing something for him or her"). It is plausible that caregivers in this study sample were challenged in being able to imagine the patient's viewpoint, which contributed toward the non-significant linkage between caregiver empathy-related responses and their perception of the patient's functional deficits.

Overall, only partial support was found for the postulated linkages in Davis' (1994) empathy model between situation factors (in this study this included patient functional deficits and caregiver emotions) and intrapersonal responses by the caregiver (in this study this included caregivers' empathy-related helping behaviours). While the researcher did not find support for the linkage between the patient's functional deficits and caregivers' empathy-related behaviours, caregiver fatigue was the only 'situation factor' that had a significant moderate negative relationship with caregivers' reports of empathy-related helping behaviours toward the affected individual with stroke. This finding has implications for clinicians in terms of identifying caregivers who experience fatigue and ameliorating the negative impact that caregiver fatigue can have on their ability to engage empathically with individuals who have been affected by stroke. Supplementary analyses found significant relationships between caregivers' mood states (anger, confusion, tension, and total emotional state) and patients' communication deficits that also have implications for clinical practice and future research which will be discussed more fully below.

Limitations

There are several study limitations that warrant further discussion as caveats for readers to carefully interpret the current study's findings. First, the study sample size was small with only 13 stroke caregivers as study participants. The researcher experienced a number of challenges in recruiting stroke caregivers which resulted in this study's small sample size. Most eligible caregiver participants did not provide the researcher with a reason for not volunteering to participate in the current study. The researcher originally aimed to recruit a minimum sample size of 20 stroke caregivers over a three month period of data collection at Riverview Health Centre. However, due to the low accrual rate, the data collection period was extended and a second recruitment site at the Stroke Recovery Association of Manitoba was added in the current study.

Second, the study sample was comprised mainly of female spousal caregivers who reported English as their first language which limits the reader's ability to generalize this study's findings to male caregivers and to caregivers of different ethnic backgrounds.

Third, all stroke caregivers were recruited from a hospital clinic and one caregiver support group. As well, post-stroke individuals and their caregivers in the current study were receiving physical and psychological supports at the time of completing the study questionnaires, which helped them in coping with post-stroke deficits and/or caregiver stress. In addition, it is important to point out that most of this study's participants are family caregivers of survivors of moderate to severe stroke. The study did not include caregivers of mild post-stroke individuals who have never been admitted to the hospital and were discharged home directly from acute care. Therefore, the study sample is likely not representative of the entire stroke caregiver population of Manitoba where many post-stroke individuals and their caregivers are not

receiving any physical or psychological supports to help them deal with or manage post-stroke care.

Strengths

Despite the current study's small sample size, the selected instruments employed in this study had good reliability estimates (i.e., all study tools had Cronbach's alpha coefficients that were $> .80$) thus lending credibility to significant findings where they existed: for example, there was a significant moderate negative relationship between caregiver fatigue as captured in the POMS tool and caregiver empathy-related helping responses as captured in the Empathy Responding Scale. Furthermore, the researcher's examination and interpretation of relationships among study variables was guided by a well-known model of empathy that was developed by Davis (1994). As well, the researcher carefully selected the POMS tool to capture both positive and negative emotions experienced by stroke caregivers. The current study's findings extend previous study findings that tended to focus more on capturing the negative emotions of caregivers.

Implications for Clinical Practice

As guided by Davis's (1994) organizational model of empathy, the overall purpose of this pilot study was to examine relationships between 'situation factors' (i.e., patient functional deficits and caregiver emotions) in the context of stroke care and caregiver empathy-related helping behaviours toward affected individuals. Although the generalizability of the researcher's findings is limited due to this study's small sample that consisted primarily female caregivers who were spouses to affected individuals, this study yielded some valuable preliminary information for clinical practice in the care of post-stroke individuals and their caregivers. In

particular, the current study's findings have implications for health care professionals to identify caregiver characteristics (e.g. caregiver fatigue) that put them at possible risk for not engaging in sensitive, empathic behaviours and responses toward post-stroke individuals when discharged into the community. Supplementary findings also suggested that deficits in patients' communication abilities are associated with negative emotions (e.g. depression) experienced by caregivers that warrant clinicians' attention and intervention.

The following recommendations offer several approaches that can be considered to formally incorporate the care of family caregivers who are vital in promoting safe and optimal care as post-stroke individuals transition to care in the home.

First, this study revealed that caregivers are able to identify multiple domains of deficits in patients affected by stroke. Physical and social participation functions were reported by family caregivers as having the highest level of functional deficits in post-stroke patients. Therefore, when seeking the caregiver's perception of the impact of stroke on the patient's quality of life, it is important for clinicians to use a multidimensional quality of life instrument. Multidimensional tools like the Stroke Impact Scale can be employed to garner family caregivers' perceptions of affected individuals' deficits to enhance caregivers' understanding and appropriate management of these stroke-related deficits in the home. Funded research of the Heart and Stroke Foundation revealed that the Stroke Impact Scale was the most comprehensive scale for assessing changes in impairments, disabilities and handicaps following stroke (Salter, Moses, Matthew, Foley, & Teasell, 2008). The completion of the scale by caregivers took about 10-20 minutes: thus, it is a reasonable tool for baseline assessment and reevaluation in the different stages of the rehabilitation process, such as at three months, six months, and one year after having stroke. In addition, the proxy version of the Stroke Impact Scale would be beneficial

for use when post-stroke individuals are unable to answer questions, or have cognitive impairment. According to Duncan et al. (2002), the Stroke Impact Scale proxy version can adequately measure post-stroke individuals' functional deficits following stroke. Indeed, the measure was designed for repeated administration to track changes over time, created to be used in clinical and research settings (Duncan, Lai, & Perera, 2002), and aimed to improve clinicians' interpretation of stroke research and their clinical decision-making (Kasner, 2006)

Also, the caregiving situation can be influenced by the caregiver's characteristics, particularly their emotional or psychological status. The researcher found only caregiver fatigue to be directly related to the level of empathy-related responses by caregivers toward post-stroke patients. This study's findings suggest that it is important for clinicians to identify caregivers who are fatigued, which can deleteriously affect their ability to provide sensitive, empathic care to post-stroke individuals. The researcher in this study employed the short version of the Profile of Mood States (which takes 5-10 minutes to complete) to capture caregivers' positive and negative emotions, including caregiver fatigue. This short version of the POMS tool is a potential tool that can provide clinicians with an economical means to identify distressed caregivers who are in need of either additional assessment, services, or referrals to other resources for coping and self-care. However, this study's findings suggest that caregivers' fatigue in particular is important to monitor in the context of stroke care. Thus, timely and accurate assessments of family caregiver's fatigue levels would be important to identify for possible intervention in support of family caregivers, so that they can continue to provide sensitive, patient-centered post-stroke care in the home. For instance, prior to discharge or transfer of care to other settings or to other health care professionals, clinicians should identify key issues that are in need of their assistance, and provide appropriate education and resources to prepare post-stroke individuals

and their caregivers for their transition of care, plus plan how to avert or ameliorate undesirable, but likely events associated with caregiving, such as caregiver fatigue, that influences the empathic support of caregivers. This can serve to prevent maltreatment of post-stroke individuals or misunderstanding patients' viewpoints by caregivers in meeting stroke care needs.

Second, this study found that post-stroke individuals' emotional status was significantly related to caregivers' emotional states. This finding has an important implication for clinicians to be aware that the emotions are likely shared between post-stroke individuals and their caregivers: i.e., when affected individuals are experiencing negative emotions, it is likely that their family caregivers also have negative emotions. Clinicians need to offer counseling or interventions that include both patients and family caregivers where they can safely explore and develop 'shared' or joint approaches to deal with their negative emotions as they arise in the context of stroke care and changes in their lives as a result of stroke.

Third, this study revealed that when caregivers perceived communication deficits in post-stroke individuals, they tended to experience increased emotional distress in general, as well as increased anger, confusion, and tension. Although caregivers in this study reported that the affected individual's communication abilities were least affected by stroke, it is important regardless for health care professionals in stroke rehabilitation to be aware of the potential impact of post-stroke individuals' communication deficits (regardless of level) on caregivers' emotions. Based on this study's findings, it appears that stroke caregivers, as a key source of support to affected individuals, need support in helping them to understand and cope with communication deficits in their loved ones. Assistance from health care professionals might include educating caregivers about communication deficits that are common consequences of stroke, as well as providing professional resources for improving the communication function of

post-stroke individuals. Future quality improvement projects might include evaluating how the impact of such formal supports affects both patient and caregiver outcomes, including long-term outcomes such as relationship quality and empathic patterns of communication, or perceptive understanding of illness experience between family caregivers and post stroke patients with communication deficits.

Implications for Future Research

The purpose of this pilot study was to conduct a preliminary examination of linkages among caregiver perceptions of the post-stroke functional status of affected individuals, caregiver emotional states, and caregiver empathy-related helping responses toward post-stroke individuals. There are several implications and recommendations for future research based on the results of this pilot study.

First, a larger sample size is needed to test relationships posited in Davis's (1994) empathy organization model that guided this pilot study: that is, associations between 'situation factors' of patient functional deficits and caregiver emotional status and caregiver engagement in empathy-related responses toward individuals affected by stroke. Future studies also need to examine relationships that can affect caregiver empathic responses as influenced by caregivers' socio-demographic characteristics, such as gender and ethnic background, which were not addressed in the current study. As well, post-stroke individuals' functional status and caregivers' emotions are likely to evolve over time. Therefore, longitudinal studies are warranted to capture experiences of affected individuals and their caregivers on the post-stroke rehabilitation journey. Longitudinal studies will also be required to assess the reliability of respective instruments to capture changes in affected individuals' and caregivers' responses over time. Ideally, these

instruments should be selected and tested for economical and reliable use by busy clinicians in clinical settings to help them assess and identify high risk caregivers for challenges in providing empathic care to the post-stroke individual.

Summary

The purpose of this pilot study was to investigate linkages among caregivers' perceptions of post-stroke individuals' functional status, caregivers' emotional states, and caregivers' empathy-related helping behaviours toward individuals with stroke. The researcher's study of relationships among study variables was guided by Davis's Empathy Organization Model (1994). Despite that this study was comprised of a small sample of caregivers ($n = 13$), this study's findings revealed that several significant associations existed among functional deficits of post-stroke patients, caregivers' emotional states, and caregivers' empathic behaviours in the context of stroke caregiving in the home. Several implications for clinical practice and future research were suggested by the researcher. To enhance the generalizability of findings to a wider range of stroke caregivers who have different characteristics and are providing care at different stages after a post-stroke, future studies need to incorporate a longitudinal design, recruit larger samples, and target family caregivers who are male and/or from varied ethnic backgrounds.

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APPENDICES

Appendix A Invitation to Family Caregivers

Recruitment site: Riverview Health Centre

(A Study by Chen Jin, RN, BN, Faculty of Nursing, University of Manitoba, Winnipeg)

Dear Family Caregivers,

My name is Chen Jin, RN, BN, and I am a Master of Nursing Student at the University of Manitoba. I am pursuing a project in partial fulfillment of my degree program at the Faculty of Nursing.

More specifically, my thesis project is about family caregivers' experiences caring for individuals who have experienced a stroke. Most nurses tend to focus on the patient's needs rather than family caregiver's needs. However, family caregivers also need help with the care and/or support of the individual who has experienced a stroke, in addition to help in dealing with their own experiences as caregivers. To know how to better support family caregivers, nurses need a better understanding of family caregivers' experiences. I will ask family caregivers of individuals who experienced a stroke to complete four questionnaires on a one-time basis only. This study has received ethical approval from the Education/Nursing Research Ethics Board at the University of Manitoba.

Family caregivers will be given several options to participate in the study outside the clinic setting. If you (as a caregiver) prefer that I help you complete the questionnaires, you can schedule a face-to-face interview with me at a date, time, and a place that is convenient to you. You also can choose to participate in an interview with me over the telephone after completing the verbal informed consent. You can also choose to complete the informed consent and questionnaires on your own and then return them to me by mail in a pre-stamped, confidential envelope that is addressed in my name that I will provide to you.

When you (as the family caregiver) agree to participate in the project, you will be asked to answer four questionnaires. The Caregiver Demographic Questionnaire will include general information about you (e.g., your age, gender); the Stroke Impact Scale will ask you to evaluate the patient's functional status after experiencing the stroke (e.g., "in the past week, how difficult is it for him/her to remember things that happened yesterday?"); the Profile of Mood State will measure your emotions (e.g., "How you have been feeling?" (Tense or Cheerful etc.); the Empathic Responding Scale will indicate what you actually do to better understand the patient's experiences (e.g., "How well do you try to understand patient's concerns?"). It will take family

caregivers approximately 20 to 30 minutes to complete the questionnaires. All the information will be confidential, and will be used for research purposes only. Your participation in this project is completely voluntary and you may withdraw from the project at any time without penalty.

Whether you would like to participate in my study or not, you can indicate your decision on the 3rd page of this invitation. You can then place this page with your response in the attached pre-stamped, confidential envelope that is addressed in my name. Please seal the envelope and return it to the clinic clerk, or by mail.

Thank you for considering this invitation. I am looking forward to hearing from you! If you have any questions about the study I can be reached at ###-#####.

Sincerely,

Chen Jin

RNBN, Master of Nursing Student

Faculty of Nursing

University of Manitoba

Invitation to Family Caregivers

(A study by Chen Jin, Faculty of Nursing, University of Manitoba)

This information is to be provided by you strictly on a voluntary basis

1) Yes, I agree to speak to the researcher (Ms. Chen Jin, Master of Nursing student, Faculty of Nursing, University of Manitoba) about participating in the study.

If yes, please provide your name and telephone number where the researcher (Ms. Chen Jin) can contact you.

Name:

Telephone Number:

2) No, I do not agree to speak to the researcher (Ms. Chen Jin) about participating in the study.

WHEN COMPLETED, PLEASE PLACE THIS FORM IN THE ATTACHED, PRE-STAMPED, CONFIDENTIAL ENVELOPE, SEAL IT AND RETURN IT TO YOUR CLINIC NURSE OR DESK CLERK. YOU CAN ALSO MAIL THE FORM TO THE RESEARCHER (MS. CHEN JIN). THANK YOU!

Appendix B Invitation to Family Caregivers

Recruitment site: Stroke Recovery Association of Manitoba

(A Study by Chen Jin, RN, BN, Faculty of Nursing, University of Manitoba, Winnipeg)

Dear Family Caregivers,

My name is Chen Jin, RN, BN, and I am a Master of Nursing Student at the University of Manitoba. I am pursuing a project in partial fulfillment of my degree program at the Faculty of Nursing.

More specifically, my thesis project is about family caregivers' experiences caring for individuals who have experienced a stroke. Most nurses tend to focus on the patient's needs rather than family caregiver's needs. However, family caregivers also need help with the care and/or support of the individual who has experienced a stroke, in addition to help in dealing with their own experiences as caregivers. To know how to better support family caregivers, nurses need a better understanding of family caregivers' experiences. I will ask family caregivers of individuals who experienced a stroke to complete four questionnaires on a one-time basis only. This study has received ethical approval from the Education/Nursing Research Ethics Board at the University of Manitoba.

Family caregivers will be given several options to participate in the study outside the clinic setting. If you (as a caregiver) prefer that I help you complete the questionnaires, you can schedule a face-to-face interview with me at a date, time, and a place that is convenient to you. You also can choose to participate in an interview with me over the telephone after completing the verbal informed consent. You can also choose to complete the informed consent and questionnaires on your own and then return them to me by mail in a pre-stamped, confidential envelope that is addressed in my name that I will provide to you.

When you (as the family caregiver) agree to participate in the project, you will be asked to answer four questionnaires. The Caregiver Demographic Questionnaire will include general information about you (e.g., your age, gender); the Stroke Impact Scale will ask you to evaluate the patient's functional status after experiencing the stroke (e.g., "in the past week, how difficult is it for him/her to remember things that happened yesterday?"); the Profile of Mood State will measure your emotions (e.g., "How you have been feeling?" (Tense or Cheerful etc.)); the Empathic Responding Scale will indicate what you actually do to better understand the patient's experiences (e.g., "How well do you try to understand patient's concerns?"). It will take family caregivers approximately 20 to 30 minutes to complete the questionnaires. All the information will be confidential, and will be used for research purposes only. Your participation in this

project is completely voluntary and you may withdraw from the project at any time without penalty.

Whether you would like to participate in my study or not, you can indicate your decision on the 3rd page of this invitation. You can then place this page with your response in the attached pre-stamped, confidential envelope that is addressed in my name. Please seal the envelope and return it to the clinic clerk, or by mail.

Thank you for considering this invitation. I am looking forward to hearing from you! If you have any questions about the study I can be reached at ###-#####.

Sincerely,

Chen Jin

RNBN, Master of Nursing Student

Faculty of Nursing

University of Manitoba

Invitation to Family Caregivers

(A study by Chen Jin, Faculty of Nursing, University of Manitoba)

This information is to be provided by you strictly on a voluntary basis

1) Yes, I agree to speak to the researcher (Ms. Chen Jin, Master of Nursing student, Faculty of Nursing, University of Manitoba) about participating in the study.

If yes, please provide your name and telephone number where the researcher (Ms. Chen Jin) can contact you.

Name:

Telephone Number:

2) No, I do not agree to speak to the researcher (Ms. Chen Jin) about participating in the study.

WHEN COMPLETED, PLEASE PLACE THIS FORM IN THE ATTACHED, PRE-STAMPED, CONFIDENTIAL ENVELOPE, SEAL IT AND RETURN IT TO YOUR DESK CLERK. YOU CAN ALSO MAIL THE FORM TO THE RESEARCHER (MS. CHEN JIN).
THANK YOU!

Appendix C Family Caregiver Consent Form

Research Project Title: The relationship between family caregivers' emotional states and ability to empathize with post-stroke individuals

Researcher: Chen Jin, RN BN, University of Manitoba, Faculty of Nursing.

Thesis Advisory Committee:

Dr. Michelle Lobchuk, Faculty of Nursing, University of Manitoba;

Dr. Wanda Chernomas Faculty of Nursing, University of Manitoba;

Dr. Sepideh Pooyania, Faculty of Medicine, University of Manitoba.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this information carefully and to understand any accompanying information.

Purpose of the study

You are invited to take part in a study about how the patient's health condition after the stroke and the caregiver's emotions might influence the caregiver's ability to understand the patient's situation after a stroke.

What am I being asked to consent to? What is the nature of my participation in the study?

You are being asked to participate in a study that involves a one-time interview at a date, time and place that is convenient to you. You have several options to complete this study's questionnaires. First, you can choose to complete the questionnaires by yourself and then mail them to Chen in a sealed, pre-stamped, addressed envelope marked confidential that will be provided to you. Second, you can choose to schedule a face-to-face or telephone meeting with Chen to complete the questionnaires at a date, time, and place that is convenient to you. The first questionnaire will ask questions about the age of you and the patient (for example, "What is the patient's age?" "What is your age?"), and caregiving relationship (for example, "How long have you been taking care of the patient (months)?"). The second questionnaire will ask you to rate the patient's functional status with questions like, "How difficult is it for him/her to remember things that happened yesterday?" The third questionnaire is about your emotional state during the caregiving process and includes questions like, "How you have been feeling (Tense or Cheerful etc.)?" The last questionnaire is about your perception as to how well you understand the individual with stroke and includes questions like, "How well do you try to understand patient's concerns?" All these questionnaires will take about 20 to 30 minutes to complete.

If you chose to have a face-to-face or a telephone interview with Chen, you should feel free to stop the interview at any time. For instance, you may decide to not complete the questionnaires (for example, if you become too fatigued or unwell to continue). If that happens, you should feel

free to ask Chen to stop the interview at any time. Chen will then provide you with the option of completing the questionnaires at another date, time and place of your convenience. If you are going to return the questionnaires by mail, you can take your time and return the completed questionnaires in the self-addressed, prepaid envelope that will be provided to you. Once Chen has finished collecting information from you, she will be willing to answer any questions that you may have about your response to questionnaires by person, or by phone.

If you would like to withdraw during the study, please feel free to inform Chen by phone or return the incomplete questionnaire and indicate, “Withdraw” on the first page of the questionnaire. You can return the incomplete questionnaires to Chen in the prepaid self-addressed envelope. The incomplete questionnaires will be treated as confidential waste. If you would like to withdraw from the study after you submitted your responses, you can contact Chen by phone. Your responses to the questionnaire will be treated as confidential waste.

Handling of information during and after the study.

Any information that you provide to Chen will be kept confidential. No personal identifying information will be recorded on any of the data collection forms used in this study. Your family (the patient) and the patient’s physician will not know how you responded. To protect your identity, you will be assigned a code number that is known only to the researcher, Chen. The code number that is linked to your name and your consent form will be locked up separately from your questionnaires. Only Chen as the researcher will know the names of individuals who have agreed to take part in the study. Only Chen, and her advisor, Dr. Michelle Lobchuk, and the statistician (Mr. Brenden Dufault, Faculty of Nursing, University of Manitoba) will have access to the questionnaires that you completed. During and after the study, all consents and questionnaires will be locked up in a secure and private location separately in the researcher’s home. According to the Master of Nursing Program policy at the Faculty of Nursing, students usually keep study material for seven years. Therefore, seven years after the completion of the study, the study data will be destroyed by shredding them, and treated as confidential waste. The results from this study may be published in a thesis document, a scientific journal, and presented at scientific meetings. However, under no circumstances will your identity be revealed. Information will be reported in aggregate or group form as opposed to individual responses. Once the research is complete, a final report of the results and how your participation helped Chen’s research will be prepared.

It is important for you to know that, in the event that abuse of children or persons in care might be discovered over the course of this study, our current law requires that Chen (as the researcher) needs to report such abuse to legal authorities.

Benefits and burden associated with participating in the study

There are no immediate benefits to you for taking part in the study. However, the results of the study may be helpful to health professionals who are interested in helping stroke individuals and family caregivers to better understand the caregiving process.

This project does not involve any more risk than you would experience in your every-day life. There is minimum risk involved to participants in the study. However, it is recognized that the

study's topic is emotional in nature. Chen will provide you with resources to help you deal with any emotional issues or answer questions that may arise as a result of participating in this study, such as the Home Care Coordinator in the Community Stroke Program (Helen Perry), and the physician in the Post Stroke Clinic in Riverview Health Centre (Dr. Pooyania).

Can I get a copy of the results of the study?

A summary of the results of the study will be made available to you if you would like to receive it once the study is completed. To indicate your interest in receiving a summary of the study, please fill out the detachable form at the end of the consent.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researcher (Ms. Chen Jin), sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. You may obtain information and clarification from the Principal Investigator (researcher) of the study, Chen Jin, RN, BN. Chen can be reached by telephone at ###-#####.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Education/ Nursing Research Ethics Board at the University of Manitoba, and the Riverview Health Center Research Review Committee to ensure that this research is in accordance with their ethical standards and regulations. If you have any concerns or complaints about this project, you may contact the researcher, Chen Jin at ###-#####; Chen's thesis supervisor Dr. Michelle Lobchuk at ###-#####; or the Human Ethics Coordinator at (204) 474-7122. A copy of this consent form has been given to you to keep for your record and reference.

I, _____, consent to participate in the study.

Participant Printed Name:

Participant Signature:

Date:

Researcher Signature:

Date:

If you would like to receive a summary of the results of this study by:

_____ **Email**

_____ **Canada Post**

Name of person to whom study results should be sent:

Mailing address:

Postal Code:

Appendix D Caregiver Demographic Questionnaire

To begin our survey, I would like to ask you a few questions about your background. We ask these questions so that we can describe the overall characteristics of the group of people who took part in the survey. **Please circle one answer (letter) or fill in the blank that corresponds with your response.**

1. What is the patient's age? (Years) _____

I prefer not to answer _____

2. What is your age? (Years) _____

I prefer not to answer _____

3. Gender: a. Female
b. Male

c. I prefer not to answer _____

4. What language do you speak most of the time at home? (What is your first language?)

A. English

B. French

C. Other (SPECIFY) _____

D. I prefer not to answer

5. What is your relationship to the patient?

a. Spouse

b. Child

c. Sibling

d. Friend

e. Parent

g. Other (specify) _____

h. I prefer not to answer

6. How many times has your loved one experienced a stroke?

a. First time

b. Second time

c. More than two times

d. I do not know

7. How long have you been taking care of the patient? (months)
 - a. 0-6
 - b. 7-12
 - c. 13-18
 - d. 19-24
 - e. >24

8. How much contact do you have with the patient?
 - a. Daily, I live with the patient
 - b. Daily, but I don't live with the patient
 - c. More than weekly, I don't live with the patient.
 - d. Weekly, I don't live with the patient.
 - e. Less than weekly, I don't live with the patient.

9. What is the extent to which you assist the patient coping with his/her stroke?
 - a. Never assist the patient
 - b. Rarely
 - c. Sometimes
 - d. Frequently
 - e. Always assist the patient

10. Do you and the patient talk openly about what the patient's thoughts and feelings are in regard to his/her stroke?
 - a. Never
 - b. Rarely
 - c. Sometimes
 - d. Frequently
 - e. Usually

11. How well do you think you know how the patient thinks or feels about his or her stroke?
 - a. Not at all
 - b. Not very well
 - c. Have some knowledge
 - d. Adequate
 - e. Very well

Appendix E Stroke Impact Scale

PROXY VERSION

The purpose of this questionnaire is to evaluate how stroke has impacted the health and life of _____ (patient name). We want to know from YOUR POINT OF VIEW how stroke has affected him/her. We will ask you questions about impairments and disabilities caused by his/her stroke, as well as how stroke has affected his/her quality of life. Finally, we will ask you to rate how much you think s/he has recovered from the stroke.

**These questions are about the physical problems
which may have occurred as a result of the stroke.**

1. In the past week, how would you rate the strength of his/her...	A lot of strength	Quite a bit of strength	Some strength	A little strength	No strength at all
a. Arm that was <u>most affected</u> by the stroke?	5	4	3	2	1
b. Grip of the hand that was <u>most affected</u> by the stroke?	5	4	3	2	1
c. Leg that was <u>most affected</u> by the stroke?	5	4	3	2	1
d. Foot/ankle that was <u>most affected</u> by the stroke?	5	4	3	2	1

These questions are about his/her memory and thinking.

2. In the past week, how difficult was it for him/her to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Remember things that people just told him/her?	5	4	3	2	1
b. Remember things that happened yesterday?	5	4	3	2	1

c. Remember to do things (e.g. keep scheduled appointments or take medication)?	5	4	3	2	1
d. Remember the day of the week?	5	4	3	2	1
e. Add and subtract numbers?	5	4	3	2	1
f. Concentrate?	5	4	3	2	1
g. Think quickly?	5	4	3	2	1
h. Solve problems?	5	4	3	2	1

These questions are about feelings, about changes in his/her mood and about his/her ability to control emotions since the stroke.

3. In the past week, how often did s/he...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Feel sad?	5	4	3	2	1
b. Feel that there is nobody s/he is close to?	5	4	3	2	1
c. Feel that s/he is a burden to others?	5	4	3	2	1
d. Feel that s/he has nothing to look forward to?	5	4	3	2	1
e. Blame her/himself for mistakes?	5	4	3	2	1
f. Enjoy things as much as s/he ever has?	5	4	3	2	1
g. Feel quite nervous?	5	4	3	2	1
h. Feel that life is worth living?	5	4	3	2	1
i. Smile and laugh at least once a day?	5	4	3	2	1

The following items are about his/her ability to communicate with other people, as well as his/her ability to understand what s/he reads and hears in a conversation.

4. In the past week, how difficult was it for him/her to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Say the name of someone whose face was in front of him/her?	5	4	3	2	1
b. Understand what was being said to him/her in a conversation?	5	4	3	2	1
c. Reply to questions?	5	4	3	2	1
d. Correctly name objects?	5	4	3	2	1
e. Participate in a conversation with a group of people?	5	4	3	2	1
f. Have a conversation on the telephone?	5	4	3	2	1
g. Call another person on the telephone, including selecting the correct phone number and dialing?	5	4	3	2	1

**The following items ask about activities
s/he might do during a typical day.**

5. In the past 2 weeks, how difficult was it for him/her to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Cannot do at all
a. Cut food with a knife and fork?	5	4	3	2	1
b. Dress the top part (waist up) of his/her body?	5	4	3	2	1
c. Bathe him/herself?	5	4	3	2	1
d. Clip his/her toenails?	5	4	3	2	1
e. Get to the toilet on time?	5	4	3	2	1
f. Control his/her bladder (not have an accident)?	5	4	3	2	1
g. Control his/her bowels (not have an accident)?	5	4	3	2	1
h. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)?	5	4	3	2	1
i. Go shopping?	5	4	3	2	1
j. Handle money (e.g. make change)?	5	4	3	2	1
k. Manage finances (e.g. pay monthly bills, manage checking account)?	5	4	3	2	1
l. Do heavy household chores (e.g. vacuum, laundry or yard work)?	5	4	3	2	1

**The following questions are about his/her ability to be mobile,
at home and in the community.**

6. In the past 2 weeks, how difficult was it for him/her to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Cannot do at all
a. Sit without losing his/her balance?	5	4	3	2	1
b. Stand without losing his/her balance?	5	4	3	2	1
c. Walk without losing his/her balance?	5	4	3	2	1
d. Move from a bed to a chair?	5	4	3	2	1
e. Get out of a chair without using his/her hands for support?	5	4	3	2	1
f. Walk one block?	5	4	3	2	1
g. Walk fast?	5	4	3	2	1
h. Climb one flight of stairs?	5	4	3	2	1
i. Climb several flights of stairs?	5	4	3	2	1
j. Get in and out of a car?	5	4	3	2	1

**The following questions are about his/her ability to use
the hand that was MOST AFFECTED by the stroke.**

7. In the past 2 weeks, how difficult was it for him/her to use the hand that was most affected by the stroke to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Cannot do at all
a. Carry heavy objects (e.g. bag of groceries)?	5	4	3	2	1
b. Turn a doorknob?	5	4	3	2	1
c. Open a can or jar?	5	4	3	2	1
d. Tie a shoe lace?	5	4	3	2	1
e. Pick up a dime?	5	4	3	2	1

The following questions are about how stroke has affected _____ (name) ability to participate in the activities that s/he would usually do, things that are meaningful to him/her and help him/her to find purpose in life.

8. During the past 4 weeks, how much of the time has s/he been limited in...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. His/her work, volunteer or other activities?	5	4	3	2	1
b. His/her social activities?	5	4	3	2	1
c. Quiet recreation (crafts, reading)?	5	4	3	2	1
d. Active recreation (sports, outings, travel)?	5	4	3	2	1
e. His/her role as a family member and/or friend?	5	4	3	2	1
f. His/her participation in spiritual or religious activities?	5	4	3	2	1
g. His/her ability to feel emotionally connected to another person?	5	4	3	2	1
h. His/her ability to control his/her life as s/he wishes?	5	4	3	2	1
i. His/her ability to help others in need?	5	4	3	2	1

9. Stroke Recovery

On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much do you feel _____ (name) has recovered from stroke?

_____	100	Fully Recovered
_____	90	

_____	80	

_____	70	

_____	60	

_____	50	

_____	40	

_____	30	

_____	20	

_____	10	

_____	0	Experienced No
	Recovery	

Appendix F Profile of Mood States 2-Adult Short

(Sample Items)

Please read each word carefully, then circle that best describes how you have been feeling during the past week, including today.

	Not at all	A little	Moderately	Quite a bit	Extremely
Active	0	1	2	3	4
Tense	0	1	2	3	4
Miserable	0	1	2	3	4
Bitter	0	1	2	3	4
Confused	0	1	2	3	4
Worn out	0	1	2	3	4

Appendix G Empathic Responding Scale

(Caregiver Perspective of Own Empathic Behavior)

How well do the following statements describe my behavior and actions (in last 4 weeks) with my ill loved one on a scale of 1 to 4, where 0 does not describe you very well and 4 describes you very well. For each question circle the number that is the best description of your actions towards your ill loved one.-----

	0	1	2	3	4
	DOES NOT DESCRIBE ME VERY WELL				DOES DESCRIBE ME VERY WELL
1. I try to understand the patient's concerns.			0	1	2 3 4
2. I try to understand how the patient felt.			0	1	2 3 4
3. I try to experience what the patient is feeling.			0	1	2 3 4
4. I try to imagine myself in the patient's shoes.			0	1	2 3 4
5. I try to see things from the patient's point of view.			0	1	2 3 4
6. I try to accept the patient as he or she is now.			0	1	2 3 4
7. I try to help the patient by listening to him or her.			0	1	2 3 4
8. I try to help the patient by doing something for him or her.			0	1	2 3 4
9. I try to figure out what would make the patient feel better.			0	1	2 3 4
10. I try to comfort the patient by telling him or her about my positive feelings for him or her.			0	1	2 3 4