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Assessing the Impact of Caregiver Outcomes on Function and Reintegration of Stroke Survivors Participating in a Community Stroke Rehabilitation Program.

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Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment of the requirements for the degree in Master of Science

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ABSTRACT

There is a limited amount of literature evaluating the relationship between caregivers, and the stroke survivors' function and reintegration. The objectives were to evaluate the association between caregivers' lifestyle changes on function and the role of functioning as a moderator between caregiving and reintegration among stroke survivors receiving community-based rehabilitation. Data were collected from January 2011 to January 2016. A one-way repeated measures analysis of variance and multivariable linear regression were performed on Functional Independence Measure, Bakas Caregiving Outcomes Scale, Reintegration to Normal Living Index across admission, discharge, and follow-up. Mean age was 70.2 ± 13.17 years with 58% males (n=200). A "change for the worst" in caregivers was associated with improvements in functioning between admission and discharge ($p < 0.001$). A "did not change" was associated with better patient reintegration between discharge and follow-up ($p < 0.05$). Low caregiver scores were associated with improved patient function and no change was associated with better patient reintegration.

Key words: Stroke, Caregiver(s), Function, Reintegration, Community-rehabilitation.

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Co-Authorship Statement

Thesis design and the research questions were formulated by Spencer Thompson under the supervisory and assistance of Dr. Susan Hunter and Dr. Robert Teasell. Data collection was performed by a research assistants at Parkwood Institute, St. Joseph's Health Care London, Ontario. Data analysis, interpretation of results, and the preparation for publication were formulated by Spencer Thompson.

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LIST OF ABBREVIATIONS

ADL: Activities of Daily Living

AFE: Absolute Functional Efficiency

AFG: Absolute Functional Gain

AVM: Arteriovenous Malformation

BCOS: Bakas Caregiving Outcomes Scale

BI: Barthel Index

CSRT: Community Stroke Rehabilitation Team

FAM: Functional Assessment Measure

FIM: Functional Independence Measure

HSF: Heart and Stroke Foundation

NSA: National Stroke Association

PHQ 9 & 2: Patient Health Questionnaire

RFE: Relative Functional Efficiency

RFG: Relative Functional Gain

RNLI: Return to Normal Living Index

VAS: Visual Analogue Scale

Chapter 1: Introduction

1.0 Overview

This study assessed the relationship between caregiver lifestyle changes and improvements in functioning in people after a stroke, in order to understand how these factors can impact patient reintegration and recovery. A stroke occurs with either an infarction or hemorrhage resulting in focal brain damage which in turn can impact neurological functions such as motor strength and control to the opposite side of the body, language or attention (Heart and Stroke Foundation of Canada, 2015).

An estimated 1.6 million Canadians are living with the effects of a stroke, with an incidence of 50,000 strokes each year (Public Health Agency of Canada, 2009). On average, a person who has had a stroke will spend less than two weeks in the acute-care hospital and due to advances in medical treatments, a large majority of stroke victims now survive and many require ongoing rehabilitation after discharge (Teasell et al., 2012). Stroke rehabilitation can help to significantly reduce disabilities arising from stroke allowing stroke survivors to regain or optimize their abilities and skills (Timbeck et al., 2003), maximizing a person's functional independence (Hershkovitz et al., 2006). After discharge from the acute-care hospital, ongoing rehabilitation can occur within an intensive inpatient setting and/or a community-based setting provided by a multidisciplinary team working in-home with the person (Allen et al., 2014; Teasell et al., 2012).

Even with optimal rehabilitation, a stroke can have a long lasting adverse impact on functional abilities with many people having difficulty completing normal activities of daily

living (ADLs). It is estimated that 68 to 74 per cent of stroke survivors depend on the daily care of family members once they return home (Bakas et al., 2006). A caregiver is defined as either a family member or a paid health-care provider, who provides physical, emotional, and personal assistance to an individual with stroke (Rigby et al., 2009). The role of a caregiver in the rehabilitation process is to provide assistance with everyday activities such as eating, cleaning, and dressing to ensure continued progress in the recovery of function of the person with stroke. The challenges associated with providing care for a person with stroke can have a negative impact on one's quality of life, both for the person with the stroke and their family members (Rigby et al., 2009). Currently, most research on caregivers has focused on the impact of stress and responsibility that caregivers take on while caring for people with stroke. Few studies have evaluated how the caregivers' well-being may affect the level of disability in stroke survivors living in the community. The following research will help to better understand the role of caregivers in the community rehabilitation process following stroke.

Several studies have assessed the impact of caring for stroke survivors on their caregivers'. However, the evaluation of the reverse relationship, the impact of caregiver life changes on stroke survivors' functional recovery, has not been investigated. Additionally, the research on the relationship between caregivers and people with stroke has been primarily focused on the assessments from admission to discharge in the acute-care hospital setting (Jeong et al., 2014; Timbeck et al., 2003). A systematic review evaluating the impact people with stroke have on their caregiver found that social support factors inconsistently contributed to burden (Rigby et al., 2009). Rigby et al. (2009) found poor functional status in the person with stroke was associated with increased caregiver burden across all phases of rehabilitation

(1-12 months post stroke). In addition, several studies identified caregiver mental health and the amount of time and effort required in caregiving as significant determinants of burden (Rigby et al., 2009). In the chronic phase of recovery after a stroke, specifically up to two years post-stroke, caregivers report an increase in emotional distress when caring for survivors who exhibit depressive symptoms and cognitive impairment (Cameron et al., 2011).

There is a lack of literature evaluating the relationship between caregivers and people with stroke following discharge from acute-care. During this critical time frame, the person with the stroke continues to receive rehabilitation and is expected to make functional gains. Furthermore, studies in stroke rehabilitation have focused on the caregiver burden, the negative impact of caring for a person with stroke, and have not considered the bi-directionality of the caregiver-stroke survivor relationship and the potential impact of the caregiver's well-being on the functional outcomes of the stroke survivor. The Bakas Caregiving Outcomes Scale (BCOS) allows for the quantification of positive and negative lifestyle changes, whereas most caregiver measures are solely focused on the negative outcomes from providing care to stroke survivors. The BCOS is a validated measure for assessing caregiver outcomes in the stroke population (Bakas et al., 1999).

There is growing evidence of the interconnectedness of couples' emotional well-being and the significance of couples-level factors like relationship quality and coping in the well-being of couples experiencing post-stroke depression (McCarthy et al., 2011). Consideration of the bi-directionality of the caregiver-stroke survivor relationship is important as studies have demonstrated individuals with post-stroke depression have significantly worse recovery in activities of daily living after two years, in comparison to stroke survivors without depression

(Parikh et al., 1990). In addition, post-stroke depression is significantly associated with stroke severity, physical disability, and cognitive impairment (De Ryck et al., 2014). Patients with relational problems have a three times greater risk of becoming depressed at 18 months post-stroke than patients without relational problems (De Ryck et al., 2014).

The current gap in the stroke literature creates an opportunity for this study to evaluate the bi-directionality of outcomes quantifiable with the BCOS and to evaluate the association between caregivers' lifestyle changes and the level of disability in persons recovering from stroke. This study offers an opportunity to analyze how caregiver outcomes impact a persons' recovery from stroke, rather than assessing what impact stroke survivors have on their caregivers.

The goal of this study is to evaluate the association between caregiver lifestyle changes on the functional gains in the stroke survivor receiving a community-based rehabilitation program, over two time periods: admission to discharge from rehabilitation and at three month follow-up from discharge. Another goal was to assess the role of functioning which will be evaluated as a moderator on the relationship between caregiving lifestyle changes and reintegration to normal living among stroke survivors receiving a community-based rehabilitation program over two time periods: admission to discharge and three month follow-up from discharge.

Chapter 2: Literature Review

This chapter will provide an overview of stroke rehabilitation and the importance of utilizing home and community-based rehabilitation to improve both caregiver outcomes and functioning in people with stroke.

2.0 Stroke

A stroke occurs from focal damage to the brain due to a disruption of the arterial blood supply, either from a blockage of blood flow or rupture of an artery to the brain (Heart and Stroke Foundation (HSF), 2015). Symptoms are a consequence of that focal brain damage and can include sudden loss of speech, weakness, or paralysis on one side of the body. Additionally, the effects of a stroke depend on the part of the brain that has been damaged and the amount of damage. There are two types of stroke: ischemic and hemorrhagic (HSF, 2015). Prognostic factors for recovery of function after a stroke include the severity of the injury, the timing of medical interventions, goals of the patient, age, and co-morbidities. Rehabilitation destinations following discharge from the acute care setting may include inpatient rehabilitation, facility-based outpatient rehabilitation, in-home community rehabilitation programs, and long-term care (Allen et al., 2014; Ring et al., 2005). Following inpatient rehabilitation some stroke survivors require ongoing therapy provided in the community to achieve their desired goals once discharged from hospital. Community-based rehabilitation may be defined as care received once the patient has passed the acute stage and has transitioned back to their home and community environment. However, in rural or remote settings, access to outpatient rehabilitation presents a significant challenge, and as such, innovative measures such as in-

home therapy can be utilized (HSF, 2015). The Heart and Stroke Foundation suggests that 10 per cent of stroke survivors recover almost completely, 25 per cent recover with minor impairments, 40 per cent experience moderate to severe impairments requiring special care, 10 per cent require care in a nursing home or other long-term care facility, and 15 per cent die shortly after the stroke (HSF, 2015).

2.1.1 Ischemic Stroke

Ischemic stroke occurs when a cerebral artery is blocked and accounts for approximately 87 per cent of all strokes (HSF, 2015). An ischemic stroke can occur in two ways (NSA, 2015). An embolic stroke occurs when a blood clot forms elsewhere in the body, almost always in the heart, and travels to the brain. Once in the brain, the embolus travels through the circulation until it reaches a blood vessel small enough to block its passage. The clot lodges there, blocking the blood flow and causing a stroke. The most common cause of an embolic stroke is atrial fibrillation. The second more common mechanism is a thrombotic stroke caused by atherosclerosis or narrowing of one of the arteries supplying blood to the brain. High blood pressure is the most important risk factor for this type of stroke (HSF, 2015) with high cholesterol levels another risk factor (NSA, 2015). Two types of blood clots can cause a thrombotic stroke: large vessel and small vessel disease. Large vessels thrombosis occurs in arteries approximately 1.0 – 2.5 cm in diameter or in muscular arteries with a thick media layer 0.3 – 1.0 cm in diameter. The most common form of thrombotic stroke occurs in the brain's largest arteries, the carotid and vertebral arteries (HSF, 2015). In most cases, it is caused by long-term atherosclerosis in combination with rapid blood clot formation. High cholesterol is a common risk factor for this type of stroke. Small vessel disease is a form of thrombotic stroke

that occurs when blood flow is blocked to a very small arterial vessel. Small arterial vessels regulate local blood flow in the body, having a diameter ranging from arterioles (10.0 μm – 0.3 cm) to capillaries, the smallest blood vessels ranging from 8.0 – 10.0 μm in the most distal segments (Morton et al. 2004).

2.0.2 Hemorrhagic Stroke

Hemorrhagic stroke results from a weakened blood vessel that ruptures causing bleeding into the brain, creating swelling and increased intracranial pressure which leads to brain damage, they account for about 13 per cent of all stroke cases (HSF, 2015). There are two types of hemorrhagic stroke, intracerebral and subarachnoid hemorrhages (HSF, 2015). An intracerebral hemorrhage occurs when a blood vessel within the brain bursts, allowing bleeding into the brain itself (HSF, 2015). Two types of weakened blood vessels usually cause hemorrhagic stroke: aneurysms and arteriovenous malformations (AVM) (NSA, 2015).

An aneurysm is defined as an excessive localized enlargement of an artery caused by a weakening of the arterial wall (HSF, 2015). An AVM is a genetic abnormality between arteries and veins which most often occurs in the brain or spine. If an AVM occurs in the brain, high pressure arterial blood stretches thin walled veins which are more susceptible to rupturing and bleeding into the brain.

2.1 Stroke Rehabilitation

Rehabilitation helps stroke survivors relearn skills that are lost after the stroke. For example, skills can include coordinating leg movements in order to walk or carrying out the steps involved in a complex activity. Rehabilitation often teaches stroke survivors new ways of

performing tasks to circumvent or compensate for any residual disabilities (Noonani et al., 2003). Individuals may need to learn how to bathe and dress using only one hand, or how to communicate effectively when their ability to use language has been compromised. There is a strong consensus among rehabilitation experts that the most important element in any rehabilitation program is carefully directed, well-focused, task-specific repetitive practice—the same kind of practice used by all people when they learn a new skill, such as playing the piano or pitching a baseball (NSA, 2015). For some stroke survivors, rehabilitation will be an ongoing process to maintain and refine skills and may involve working with specialists for months or years after the stroke (Noonani et al., 2003).

2.2 Stages of Stroke Rehabilitation

The timing of rehabilitation is thought to influence stroke recovery. In the context of stroke rehabilitation, acute rehabilitation refers to the time frame of stroke onset to one month (Duncan et al., 2000; Winstein et al., 2016) , but is often regarded as the first 10-14 days following a stroke (Kwakkel et al., 2006). The sub-acute phase has been defined as the window in which time-dependent spontaneous neurological recovery still occurs, this is typically within the first 10 weeks up to six months after stroke onset (Winstein et al., 2016). During this phase of rehabilitation, the severity of the stroke, intensity of therapy, and timing of interventions all influence functional recovery (Brock et al. 2002; Gubitz et al., 2000). Chronic stroke refers to any time point beyond six months as it is understood cessation or reduction in progress occurs during this stage. However, a review of the literature suggests that with continued rehabilitation that an optimization of the function beyond the proposed six month plateau is possible (Teasell et al., 2012).

2.2.1 Acute

Meta-analyses support a reduction in mortality for individuals treated by specialized stroke services compared with control groups who received usual care. Patients who were managed within a stroke unit were more likely to survive, return home, and regain independence in everyday activities (Seenan et al., 2007). A reduction in mortality (Seenan et al., 2007) and the combined outcome of death or institutional-care occur with specialized stroke services (Cochrane Collaboration, 2007). One meta-analysis (Noonani et al., 2003) also indicated increased odds of a stroke survivor returning to their own home following discharge from a specialized stroke program. It has been widely demonstrated that acute stroke rehabilitation can have an enormous influence on both the improvement in function and quality of life for the stroke survivor, but also provides benefits related to well-being for family members and caregivers (Noonani et al., 2003).

2.2.2 Sub-Acute

Several studies have examined the impact of sub-acute stroke rehabilitation therapies aimed at improving specific stroke-related deficits. Participation in sub-acute rehabilitation is related to an increased independence in activities of daily living, (Corr et al., 1995; Logan et al., 1997; Walker et al., 2001) improved social outcomes, (Forster et al., 1996) lower hospital readmission rates, (Andersen et al., 2000) improved depression and anxiety symptoms, (Ricauda et al., 2004) fewer medical complications, (Chaiyawat et al., 2004) and greater functional improvement (Green et al., 2002) as compared with control groups receiving no further therapy after the acute phase of recovery.

2.2.3 Chronic

Studies of recovery in the chronic phase of stroke are fewer than those in the acute and sub-acute stages. The evaluation of outpatient rehabilitation outcomes during the chronic stage of stroke recovery (less than six months post stroke) have demonstrated significant improvements in activities of daily living, mobility, (Green et al., 2002; Wade et al., 1992) and functional independence (Werner et al., 1996).

2.3 Community and Home-based Stroke Rehabilitation

Stroke rehabilitation for people living in the community is commonly delivered either in an inpatient setting, outpatient, or day-hospital setting. Services may be offered as home-based or domiciliary rehabilitation with differing reports of the benefits and barriers of home-based therapy compared to inpatient or outpatient rehabilitation. The literature appears to support cost benefits and increased caregiver satisfaction of home-based rehabilitation (Allen et al., 2014).

An issue which has been noted in the evaluation of community-based and home-based rehabilitation programs is that few studies detail the content of the actual interventions used in the rehabilitation programs; a situation not only unhelpful for therapists, but one which makes the designing of future trials difficult. Furthermore, stroke rehabilitation in the community is frequently termed “home”- or “domiciliary”- based, and often represents community-based rehabilitation as defined by the World Health Organization (programs which support people with disabilities in attaining their highest possible level of health, working across key areas of health promotion, medical care, rehabilitation and assistive devices) (Khasnabis and Motsch,

2010). It is suggested that centre-based community programs may result in different outcomes to home-based programs (Hale et al., 2004).

2.3.1 Community Stroke Rehabilitation Teams

Community stroke rehabilitation teams (CSRT) work collaboratively with service providers in the community to ensure stroke survivors have the appropriate therapy, education, and support. Evidence from the use of CSRT indicates that clients may access fewer health care resources over time (Allen et al., 2014), such as readmission to hospital, emergency room visits, general physician visits, and other social services. There may also be decreased costs to the patient due to fewer travel costs, private therapies accessed, and loss of employment wages, particularly accrued by family members who often provide transportation to the outpatient facility. It is hypothesized that the upfront cost of the CSRT to the health care system is greatly offset over time by cost savings in these other areas (Allen et al., 2014; St. Joseph's Health Care London, 2015).

2.4 Caregivers

2.4.1 What is a caregiver?

As previously stated, a stroke can have a lifelong impact on functional abilities, with many individuals having trouble achieving independence in everyday tasks. It is estimated that 68 to 74 percent of stroke survivors depend on the daily care of family members once they return home (Bakas et al., 2006). A caregiver is a person, either a family member or a paid health care provider, who provides physical, emotional, and personal assistance to a patient with stroke (Rigby et al., 2009). The caregiver has an important role to play throughout the time

frames of recovery after the stroke. The role of a caregiver in stroke rehabilitation is to provide assistance in activities of daily living and to facilitate continued progress towards recovery. The challenges associated with providing care for a patient with stroke can negatively impact quality of life, both for the person with the stroke and their family members (Rigby et al., 2009).

2.4.2 What impact do caregivers have on stroke survivors?

The impact of caregiver life changes on stroke survivors has rarely been investigated. Moreover, the relationship between caregivers and stroke survivors' functional gains has primarily focused on the time frame from admission to discharge of the acute care hospital setting (Jeong et al., 2014; Timbeck et al., 2003) or in the chronic phase many years after the stroke (Teasell et al., 2012). At two years post-stroke, caregivers report increased emotional distress when caring for survivors exhibiting depressive symptoms and cognitive impairment (Cameron et al., 2011). A systematic review evaluating the impact people with stroke have on their caregiver found that social support factors inconsistently contribute to burden (Rigby et al., 2009). In addition, several studies identified caregiver mental health and the amount of time and effort required of the caregiver as significant determinants of burden (Rigby et al., 2009).

2.5 Caregiver Burden

A considerable amount of research has been conducted on the impact of caregivers' depression on people with stroke. To date, 68 studies have assessed the impact of caring for stroke survivors and the relationship with caregivers' depression. In the evaluation of gender differences, results suggest that husbands who suffered from a stroke were unaffected by their

wives' health (Ayotte et al., 2010). Cameron et al. (2011) state that overall, caregivers report a rise in emotional distress when caring for stroke survivors exhibiting increased depressive symptoms and cognitive impairment. Moreover, there is a lack of literature evaluating sub-acute rehabilitation for the effects of the caregivers' burden on the people with stroke. It is essential to understand not only what positive or negative changes the caregiver experiences, but how these changes will affect the stroke survivors' progression once they return to their homes or to the community.

2.6 Quantification of Caregiver Lifestyle Changes and Caregiver Burden

A New Zealand-based study suggests that although there is evidence that stroke rehabilitation in the community significantly improves personal and extended activities of daily living with decreasing functional deterioration, there is some indication that this model of service delivery may result in greater caregivers stress (Hale et al., 2004). Visser-Meiley et al. (2004) conducted a review and assessed the clinometric properties of caregiver scales in stroke rehabilitation populations. The clinometric properties are quantitative measurements of clinical and personal phenomena of patient care through collection and analysis of comparative clinical data (Visser-Meiley et al. 2004). The authors found 16 separate outcome measures evaluating the burden of caregiving experienced by caregivers of people with stroke. Visser-Meiley et al. (2004) concluded that no measure has proven superiority above others suggesting future research should focus on comparisons between existing instruments and their levels of reliability and responsiveness. Furthermore, the authors state that all burden scales include items concerning aspects of competence, negative feelings, mental and physical health, social relations, social problems and economic aspects, but there are clear differences in the main

focus between these scales. The BCOS, Caregiving Burden Scale and Caregiving Strain Index emphasize the social consequences of caregiving more than other scales. In scales developed for caregivers of elderly people, like the Burden Interview Index, the Relative Stress Scale (RSS), the Sense of Competence Questionnaire and the Caregiver Reaction Assessment, more than 40 per cent of the items belong to the negative feelings and competence category. This bias might limit their validity for caregivers of stroke patients, although a comparison between caregivers of elderly stroke and people living with dementia showed no significant differences in RSS scores (Visser-Meiley et al., 2004).

Family caregivers of stroke survivors experience greater levels of depression, emotional problems, social inactivity, and general ill health compared to non-caregiving individuals (Bakas et al., 1999). While numerous instruments measure these variables in family caregivers, they are often too global, indicating the need for an instrument measuring life changes in care providers (Bakas et al., 1999).

The BCOS measures lifestyle changes of a caregiver in relation to emotional well-being, ability to cope with stress, self-esteem, relationship with friends and family, physical health, time for social activities, future outlook, and relationship with care recipient. The measure has 10 items each graded on a seven-point Likert scale from negative three to positive three with scores ranging from -30 to 30. This scoring method allows for both the quantification of positive and negative life changes; in contrast, most caregiver measures are solely focused on the negative outcomes from providing care to people with stroke. The BCOS, while not developed specifically for the stroke population, is a validated measure for assessing caregiver outcomes in a stroke population (Bakas et al., 1999).

2.7 Changes in Functioning Post Stroke

Functioning is defined as the stroke survivors' ability to move around in the environment which includes participation in activities of daily living (ADL) and getting from place to place (McDowell & Newell, 1996). Movements include standing, bending, walking, and climbing. To date, 41 outcome measures have been used to assess functional mobility in people with stroke (Herbert et al., 2016). Although multiple measures are available for use, the Canadian Stroke Best Practice Guidelines suggest the Functional Independence Measure (FIM) should be used for the assessment of functional disability in people with stroke (Herbert et al., 2016; StrokEDGE Task Force, 2010; 2011).

2.7.1 Quantification of Functioning

The Functional Independence Measure (FIM) is a measurement of disability with items scored on how much assistance is required for an individual to carry out ADLs. The FIM was developed to offer a uniform system of measurement for disability based on the International Classification of Impairment, Disabilities, and Handicaps for use within the medical system in the United States (McDowell & Newell, 1996).

The FIM was also developed to address issues of lack of sensitivity and comprehensiveness within the Barthel Index (BI), an earlier developed measure of function considered to be problematic (Beninato et al., 2006; van der Putten et al. 1999). The FIM assesses six areas of function (self-care, sphincter control, mobility, locomotion, communication, and social cognition). The FIM is scored on a 7-point Likert scale grading the amount of assistance required to perform each item (1 = total assistance in all areas, 7 = total

independence in all areas) (McDowell & Newell, 1996). The ratings are based on performance rather than capacity and can be acquired by observation, patient interview, telephone interview, or medical records. It is a valid and reliable measure for use in people with stroke, traumatic brain injury, spinal cord injury, multiple sclerosis, and elderly individuals undergoing inpatient rehabilitation and has been used with children as young as seven years old. The FIM has been shown to be a valid and reliable measurement for disability (Brosseau et al. 1994; Corrigan et al., 1997; Kidd et al., 1995).

The developers of the FIM recommend that the scoring be derived by consensus within a multi-disciplinary team. A final summed score is created which can range from 18 to 126, where 18 represents complete dependence/total assistance and 126 represents complete independence. There are three values typically reported for the FIM, a total FIM score and two sub-scale scores of FIM-motor with 13 motor tasks and FIM-cognitive encompassing five cognitive tasks.

For the FIM-motor sub-scale, the eating, bowel management, and grooming items are known to be the easiest items for people with stroke to accomplish, whereas locomotion, tub transfers, and stair climbing are the most challenging items (Granger et al., 1993; Grimby et al., 1996). For the FIM-cognitive sub-scale, performance of the expression items has been found to be the easiest for people with stroke to accomplish with problem solving the most challenging (Granger et al., 1993).

2.8 Post-Stroke Depression

Many stroke survivors experience feelings of anger, frustration, anxiety, sadness, fear, and hopelessness in varying degrees (Kroenke et al, 2001). These emotions are common presentations in post-stroke depression, which affects more than a third of stroke survivors, (Cheng et al., 2010) and according to the National Institute of Health (2008) post-stroke depression is often underdiagnosed.

2.8.1 Quantification of Post-Stroke Depression

The diagnostic validity of the 9-item PHQ-9 was established in a study involving 15 clinics involving 3,636 patients, 18 years or older, who participated in the PHQ Primary Care Study. Reliability and validity of the tool has indicated sound psychometric properties of all patients admitted to primary care, but it has not been specifically evaluated in stroke patients (Kroenke et al., 2001). However, recent studies have supported the use of the PHQ-9 within stroke survivor populations (May et al., 2017). The tool is made up of nine questions with four response options, ranging from 0-3 on each questions and a total score ranging from 0-27. Any scores from 0-9 indicate minimal depressive symptoms, 10-14 minor depression, 14-19 moderate depression, and any score over 20 indicates a major depressive disorder (Kroenke et al., 2001). PHQ-9 scores greater than 10 have a sensitivity of 88 per cent and a specificity of 88 per cent for identifying a major depressive disorder (Kroenke et al., 2001). Results from these interviews showed that individuals who scored high on the PHQ-9 were between 7 to 13.6 times more likely to be diagnosed with depression by a mental health professional. On the other hand, individuals scoring below four on the PHQ-9 had a less than a 1 in 25 chance of

having depression (Kroenke et al., 2001). The PHQ-2, comprising the first two items of the PHQ-9 asks about the degree to which an individual has experienced a depressed mood over the past two weeks (Kroenke et al., 2003). The purpose of the PHQ-2 is screen for depressive symptomatology. Patients who screen positive on the PHQ-2 should be further evaluated with the PHQ-9 to determine whether they meet criteria for a depressive disorder. The PHQ-2 has been validated in three studies showing wide variability in sensitivity (Gilbody et al., 2007).

2.9 Patient Reintegration

Patient reintegration or the process of community integration is defined as the participation in a home-like setting, enjoyment of a social network, and engagement in productive activities (Tooth et al., 2003). Furthermore, rehabilitation has shifted from a focus on basic function to the performance of more complex activities of daily living, psychological and social health, and overall well-being (Tooth et al., 2003). The shift now focuses on *“reorganization of physical, psychological, and social characteristics of an individual into a harmonious whole so that one can resume well-adjusted living after incapacitating illness or trauma”* (Wood-Dauphinee & Williams, 1987, p. 10) that is contained within the idea of reintegration.

2.9.1 Quantification of Reintegration

The Reintegration to Normal Living Index (RNLI) was developed to assess the degree to which individuals who have experienced traumatic or incapacitating illness achieve reintegration into their normal social activities (Wood-Dauphinee & Williams, 1987).

The RNLI is a reliable and validated tool for use with individuals with stroke and other health conditions (Mayo et al., 2002). The RNLI index consists of 11 declarative statements, with the following domains: indoor, community, and distance mobility; self-care, daily activity (work and school), recreational and social activities, family role(s), personal relationship, presentation of self to others, and general coping skills. The first eight items represent 'daily functioning' and the remaining three items represent 'perception of self'. In terms of scoring, each domain is accompanied by a Visual Analogue Scale (VAS) (0 to 10 cm). The VAS is anchored by the statements "does not describe my situation" (1 or minimal integration) and "fully describes my situation" (10 or complete integration). Individual item scores are summed to provide a total score out of 110 points that are proportionally converted to create a score out of 100. Three- and four-point categorical scoring systems were also developed (Wood-Dauphinee et al., 1988), and the three-point categorical system has been used in the evaluation of people with stroke (Mayo et al., 2000; Mayo et al., 2002). In the three-point system, an additional category is inserted between the two anchor points ("partially describes my situation") and the respondent selects the most applicable of the three categories. This option yields total scale scores from 0-22, with higher scores indicating better reintegration (Mayo et al., 2000, Mayo et al., 2002).

There are two subscales to the RNLI: daily functioning (indoor, community, distance mobility, self-care, daily activity (work and school), recreational and social activities, and general coping skills) and perception of self, (family role(s), personal relationships, and presentation of self to others).

Chapter 3: Objective and Hypothesis

3.0 Objectives

1. To evaluate the association between caregiver lifestyle changes on the functional gains in the stroke survivor receiving a community-based rehabilitation program, over two time periods: admission to discharge from rehabilitation and at three months follow-up from discharge.
2. To evaluate the role of functioning as a moderator on the relationship between caregiving lifestyle changes and reintegration to normal living among stroke survivors receiving a community-based rehabilitation program over two time periods: admission to discharge and three months follow-up from discharge.

3.1 Hypothesis

Patients receiving community stroke rehabilitation and whose caregivers demonstrate positive lifestyle changes, as measured by the Bakas Caregiving Outcomes Scale (BCOS), will demonstrate greater functioning as measured by the Functional Independence Measure (FIM), resulting in better reintegration measured by the Reintegration to Normal Living Index (RNLI) from admission to follow-up.

Chapter 4: Methodology

4.0 Study Design

A retrospective cohort study through chart audit of all patient admissions to the Community Stroke Rehabilitation Team (CSRT) Program, Parkwood Institute, St. Joseph's Health Care London, Ontario, Canada was conducted. CSRT provides therapy for adults recovering from stroke. Partnering very closely with the Community Care Access Centre and primary care providers, CSRT provides integrated, individualized care for stroke survivors in the community (St. Joseph's Health Care London, 2015). Parkwood Institute serves as the primary provider of rehabilitation programs for stroke survivors in London and the surrounding areas. The CSRT program had over 600 referrals in 2015 of which about half received four or more therapy visits (an average of 29 visits per patient) (St. Joseph's Health Care London, 2015; Allen et al., 2014). Each CSRT consists of members from eight different disciplines: physiotherapist, occupational therapist, speech-language pathologist, therapeutic recreation specialist, rehabilitation therapist, registered nurse, or social worker (St. Joseph's Health Care London, 2015).

The data in the patient charts were completed by the attending care provider(s). Data were collected for admission, discharge, and three months follow-up after discharge during the period of January 2011 to January 2016 and included 1502 individuals. A minimum of four visits was required, this included the three assessments and one therapeutic visit. Ethics approval was received from University of Western Ontario Health Sciences Research Ethics Board (HSREB). (See Appendix 1: Ethics Approval)

4.1 Study Population

Participant inclusion to the CSRT program was based on the following criteria:

1. Adult stroke survivors (over 18 years of age), who consented and was motivated to participate in the program;
2. Medically stable;
3. Reside in: Elgin, Middlesex, Oxford, SW Norfolk, Huron, Perth, Bruce, and parts of Grey counties;
4. The patients' needs were best met by specialized stroke rehabilitation services in the community (St. Joseph's Health Care 2015).

Participant exclusion criteria for the CSRT program was based on the following criteria:

1. Under 18 years of age;
2. Medically unstable;
3. Lived outside Southwestern Ontario;
4. Did not require specialized stroke rehabilitation services within the community (St. Joseph's Health Care 2015).

4.2 Criteria for retrospective data analysis

Data were included in the analysis if:

1. Patient received four or more visits from CSRT;
2. Patients had complete demographic information;
3. Suffered from a stroke;

4. A caregiver was present at all three time points; and
5. Complete information on RNLI, FIM, and BCOS outcome measures at all three time points.

Data were excluded in the analysis if:

1. Received less than four visits from CSRTs ;
2. Incomplete information on RNLI, FIM, or BCOS outcome measures across all three time points;
3. Any demographic information was missing;
4. Suffered from a transient ischemic attack or unknown stroke type;

(See Appendix 5: Flow Chart Overview for generation of data set used for study n=200)

4.3 Outcome Measures

4.3.1. Data Derived From the Chart Audit

i) Caregiver Outcome Measure: Bakas Caregiving Outcomes Scale (BCOS) has 10 items, each scored on a 7-point scale, which measures life changes resulting from caregiving in relation to emotional well-being, ability to cope with stress, self-esteem, relationship with friends and family, physical health, time for social activities, future outlook, and relationship with care recipient (Bakas et al., 1999). Scores can range from -30 - 30, with the minimum score indicating a “change for the worst” and maximum score indicating a “change for the best”. The BCOS data collected has open ended questions from items 11-15, which varied by participant. Therefore, the 10-item BCOS was used to ensure the tool was comparable across all participants. The BCOS

scores were recoded from the original -3 to 3 to reflect positive score ranging from 1 to 7. The 1-7 scale was used to calculate mean and change scores to overcome the limitation of negative values in calculating changes scores. Therefore, BCOS scores ranged from 10-70 rather than -30 to 30. (See Appendix 2 for a copy of the BCOS assessment form)

ii) Measurements of Disability: Functional Independence Measure (FIM) is a measurement of the patients' level of disability and is the established standardized outcome measure in Canadian rehabilitation settings. Items are scored based on how much assistance is required for the individual to carry out activities of daily living (Keith et al., 1987). A final summed score is created and ranges from 18 - 126, where 18 represents complete dependence or total assistance and 126 represents complete independence. The FIM consists of 18 items assessing six areas of function which fall into two domains: Motor (13 items) and Cognitive (5 items) and are referred to as the Motor-FIM and the Cognitive-FIM. (See Appendix 3 for a copy of the FIM assessment form)

iii) Measures of Reintegration: The Reintegration to Normal Living Index (RNLI) was developed to assess the degree to which individuals who have experienced traumatic or incapacitating illness achieve reintegration into normal social activities (Wood-Dauphinee & Williams, 1987). The RNLI is a valid and reliable measure available in Canadian English and Canadian French (Daneski et al. 2003; Wood-Dauphinee & Williams, 1987; Wood-Dauphinee et al., 1988). The RNLI index is made up of 11 declarative statements, including the following domains: indoor, community, and distance mobility; self-care, daily activity (work and school), recreational and social activities, family role(s), personal relationship, presentation of self to others, and general coping skills. The first eight items represent 'daily functioning' and the remaining three items

represent 'perception of self'. A three-point categorical system has been used in the evaluation of people with stroke (Mayo et al., 2000; Mayo et al., 2002). In the three-point system, a category is inserted between the two anchor points and the respondent selects the most applicable of the three categories. This option yields total scale scores from 22-0, with higher scores indicating better reintegration (Mayo et al., 2000, Mayo et al., 2002). (See Appendix 4 for a copy of the RNLI assessment form)

iv) Demographic Information: Age, gender, and marital status (single, married, common law, divorced, widowed, separated). Rehabilitation Information: referral source (acute, inpatient rehabilitation, outpatient rehabilitation, community, Community Care Access Centres (CCAC), long-term care), stroke type (ischemic, hemorrhagic), number of visits (physiotherapist, occupational therapist, speech-language pathologist, therapeutic recreation specialist, rehabilitation therapist, registered nurse, and social worker, total), and intensity (visits/week).

4.3.2 Variables Calculated from Chart Audit Data

i) Caregiver Scores as Exposure of Interest

Due to the bi-directionality of BCOS, a categorical variable was created to account for change between admission and discharge and discharge to follow-up of those who: "change for the worst" = -1, "did not change" = 0, and "change for the best" = +1.

ii) Change Scores in Functional Status

A change score is the difference between the values of a variable measured at one point in time and at another time point (for example, admission (ADM) or discharge (DC)). Change in function, as quantified using the FIM, was evaluated using several different metrics.

Rehabilitation outcomes can be evaluated as both absolute and relative gains in function, to address ceiling effects within the FIM (Muir-Hunter et al., 2016; Koh et al., 2013). The FIM score was used as the basis for five measures of both absolute and relative rehabilitation gains that were evaluated in Objective 1.

1. Absolute functional gain (AFG), is the total number of points change in the FIM score between two time points. The value was calculated for time one (admission to discharge) and time two (discharge to follow-up) (Koh et al., 2013):

$$\text{AFG} = \text{DC (FIM)} - \text{ADM (FIM)}$$

2. AFG percentage, is the percentage change in the FIM score between admission and discharge and discharge to follow-up (Handoll et al., 2009; Koh et al., 2013):

$$\text{AFG\%} = \frac{\text{DC (FIM)} - \text{ADM (FIM)}}{126} \times 100\%$$

3. Absolute functional efficiency (AFE), is the difference in the FIM score between admission and discharge and discharge to follow-up dates expressed as the total number of points change per day of CSRT stay (Koh et al., 2013):

$$\text{AFE} = \frac{\text{DC (FIM)} - \text{ADM (FIM)}}{\text{DateDC} - \text{DateADM}}$$

4. Relative functional gain (RFG), is the difference between the maximum possible FIM score and the admission FIM score (Muir-Hunter et al., 2016; Koh et al., 2013):

$$\text{RFG} = \frac{\text{DC (FIM)} - \text{ADM (FIM)}}{\text{Max (FIM)} - \text{ADM (FIM)}} \times 100\%$$

5. Relative functional efficiency (RFE), is the RFG expressed as the total number of points change per day of CSRT stay (Muir-Hunter et al., 2016; Koh et al., 2013):

$$\text{RFE} = \frac{\text{DC (FIM)} - \text{ADM (FIM)}}{\text{Max (FIM)} - \text{ADM (FIM)}} \times \frac{1}{\text{LOS}}$$

4.4 Statistical Analysis

Demographic data were summarized using means and standard deviations or frequencies and percentages, as appropriate, for the sample based on values obtained at admission to rehabilitation.

An initial analysis of the data consisted of a one-way repeated measures analysis of variance (ANOVA) to determine difference on each of the variables of BCOS, FIM, and RNLI across the three time points of admission, discharge, and follow-up. Statistically significant findings from each of the three ANOVA analyses were followed up by post-hoc pair-wise comparisons using Bonferroni correction to adjust for multiple comparisons. The differences between groups were given superscript letters, such that values with different letters indicate statistically significance difference from one another. A graphical presentation of the change in

individual FIM scores was constructed across the three time frames of admission to discharge, discharge to follow-up and admission to follow-up.

The first set of analyses for Objective one evaluated the change in function between the time points of admission to discharge (FIM2) and discharge to follow-up (FIM3). The exposure of interest, caregiving lifestyle changes, was modeled as BCOS1 (admission score) and Δ BCOS 1-2 (change from admission to discharge) on the outcome FIM2. Caregiving lifestyle changes were also modeled as BCOS2 (discharge score) and Δ BCOS 2-3 (change from discharge to follow-up) on the outcome FIM3. Analysis of covariance (ANCOVA) regression modeling was used to evaluate: i) the association between FIM2 and BCOS1 and Δ BCOS 1-2, and ii) the association between FIM3 and BCOS2 and Δ BCOS 2-3. This modeling yielded a total of 4 models in both unadjusted and adjusted analyses.

A second set of analyses were performed for Objective one with the FIM score modeled as the five absolute and relative change scores variables outlined in Section 4.3.2. Change in function was again evaluated over the two time frames of admission to discharge (time frame 1) and discharge to follow-up (time frame 2). For each of the computed relative and absolute change score variables three regression models were generated, unadjusted and adjusted analyses. The independent variables for the first time frame were: BCOS1 (score at admission), BCOS2 (score at discharge), and the change in BCOS from admission to discharge (Δ BCOS 1-2). The independent variables for the second time frame were: BCOS2 (score at discharge), BCOS3 (score at follow-up) and the change in BCOS from discharge to follow-up (Δ BCOS 2-3). A fourth regression model was performed for absolute functional gain and absolute functional gain percentage from admission to discharge (AFG 1, AFG% 1) and discharge to follow-up (AFG 2,

AFG% 2). The independent variables were BCOS scores as a categorical value with three levels indicating the bi-directionality of scores (see Section 4.3.2). Caregivers who “changed for the worst” between admission and discharge (Δ BCOS -), discharge to follow-up (Δ BCOS – T2), caregivers who had “did not change” from admission to discharge (No Δ BCOS), discharge to follow-up (No Δ BCOS T2), and “change for the best” = +1. (See Section 4.3.2) The new categorical BCOS variable was modeled as two dummy variables, BCOS “did not change” and BCOS “change for the worst”, referenced to BCOS “change for the best”. Unstandardized regression coefficients were recorded and regression diagnostics were performed to ensure model fit. In total, the regression modeling yielded a total of 17 models in both unadjusted and adjusted analyses. (See Appendix 7. for scatterplots)

The first set of analyses to address Objective two evaluated the change in reintegration between the time points of admission to discharge (RNLI 2) and discharge to follow-up (RNLI 3). The exposure of interest, caregiving lifestyle changes, was modeled as BCOS1 (admission score) and Δ BCOS 1-2 (change from admission to discharge) on the outcome RNLI 2. Caregiving lifestyle changes were also modeled as BCOS2 (discharge score) and Δ BCOS 2-3 (change from discharge to follow-up) on the outcome RNLI 3. Analysis of covariance (ANCOVA) regression modeling was used to evaluate: i) the association between RNLI 2 and BCOS1 and Δ BCOS 1-2, and ii) the association between RNLI 3 and BCOS2 and Δ BCOS 2-3. This modeling yielded a total of four models in both unadjusted and adjusted analyses.

The second set of analyses to address Objective two evaluated the FIM score as a moderator between the association of BCOS and RNLI. Analysis of covariance (ANCOVA) regression modeling was used to evaluate: i) the association between RNLI 2 and FIM2 and

Δ BCOS 1-2, and ii) the association between RNLI 3 and FIM 3 and Δ BCOS 2-3. This modeling yielded a total of 4 models in both unadjusted and adjusted analyses.

The final analyses for Objective two were repeated to explore the change in the BCOS scores as a categorical value with three levels indicating the bi-directionality of scores. Caregivers who “changed for the worst” between admission and discharge (Δ BCOS -), discharge to follow-up (Δ BCOS – T2); caregivers who “did not change” from admission to discharge (No Δ BCOS), discharge to follow-up (No Δ BCOS T2); and “change for the best” was used as the reference category. Dependent variables were the RNLI discharge (RNLI 2), and RNLI follow-up (RNLI 3). Additionally, included FIM discharge (FIM 2) and FIM follow-up (FIM 3) as independent variables for the assessments of FIM as a moderator in the relationship between BCOS and RNLI.

For the adjusted regression modeling (both ANCOVA and multivariable linear regression), the variables included for confounding control were: age, the age of the patients upon admission to the CSRT; total number of visits, the total of all eight members from the CSRT visits; intensity, the amount of time spent with the patient during each visit; length of stay, how long each participant remained in the program; time since stroke, the difference of the admission date to the date of the participants’ most recent stroke; and residence, a categorical variable with four levels describing where the participant lived when admitted to the program. (See Appendix 6. Conceptual Model). Three methods were used to identify the minimum set of variables for confounding control. Causal modeling was used to explore the theoretical relationships between variables and the exposure/outcome of interest. A mathematical determination of change in the value of the beta coefficient of interest of the

exposure by 10 per cent or greater was used to identify relevant confounding factors. Lastly, existing literature was used to decide which confounding variables would be included in the adjusted models.

All data analysis was carried out using IBM Statistic Package for the Social Sciences (SPSS) version 23.0 software (SPSS, Chicago, IL).

Chapter 5: Results

The study contained a sample of 200 participants, age ranged from 30- 94 years; mean age = 70.16 (\pm 13.17); 58 per cent were male with 77.50 per cent suffering an ischemic stroke (155). Participants received on average 34.27 (\pm 19.91) visits from CSRT with the highest amount of visits from rehabilitation therapists with 8.83 (\pm 9.41) and least number of visits from social workers at 2.55 (\pm 4.59).

Table 1. Summary of Sample Characteristics (n=200)

Category	Summary Value
Gender (n, %)	M: 116 (58.0%) F: 84 (42.0%)
Age (years)	70.16 \pm 13.17
Stroke Type	Ischemic: 155 (77.50 %) Hemorrhagic: 45 (22.50%)
Time Since Stroke (months)	2.16 \pm 2.21
Number of Therapeutic Visits Provided by Community Stroke Rehabilitation Team	
Physiotherapy Visits	4.15 \pm 5.41
Occupational Therapy Visits	4.22 \pm 4.39
Speech-Language Pathology Visits	2.72 \pm 4.64
Registered Nurse Visits	3.36 \pm 3.17
Social Worker Visits	2.55 \pm 4.59
Therapeutic Recreational Specialist Visits	3.18 \pm 4.59
Rehabilitation Therapist Visits	8.83 \pm 9.41
Total Visits	34.27 \pm 19.91
Outcome Measures	
Functional Independence Measure Admission	103.15 \pm 22.01
Functional Independence Measure Discharge	101.02 \pm 20.44
Functional Independence Measure Follow-up	110.28 \pm 15.68
Bakas Caregiving Outcomes Scale Admission	37.35 \pm 7.39
Bakas Caregiving Outcomes Scale Discharge	41.14 \pm 12.19
Bakas Caregiving Outcomes Scale Follow-up	40.12 \pm 10.88
Reintegration to Normal Living Index Admission	15.10 \pm 4.387
Reintegration to Normal Living Index Discharge	17.93 \pm 3.68
Reintegration to Normal Living Index Follow-up	18.61 \pm 3.39

Figure 1. Line graphs for change in Functional Independence Measure (FIM) scores from: A) Admission (ADM) to Discharge (DC), B) Discharge (DC) to Follow-up (FU), C) Admission (ADM) to Follow-up (FU). (n=200)

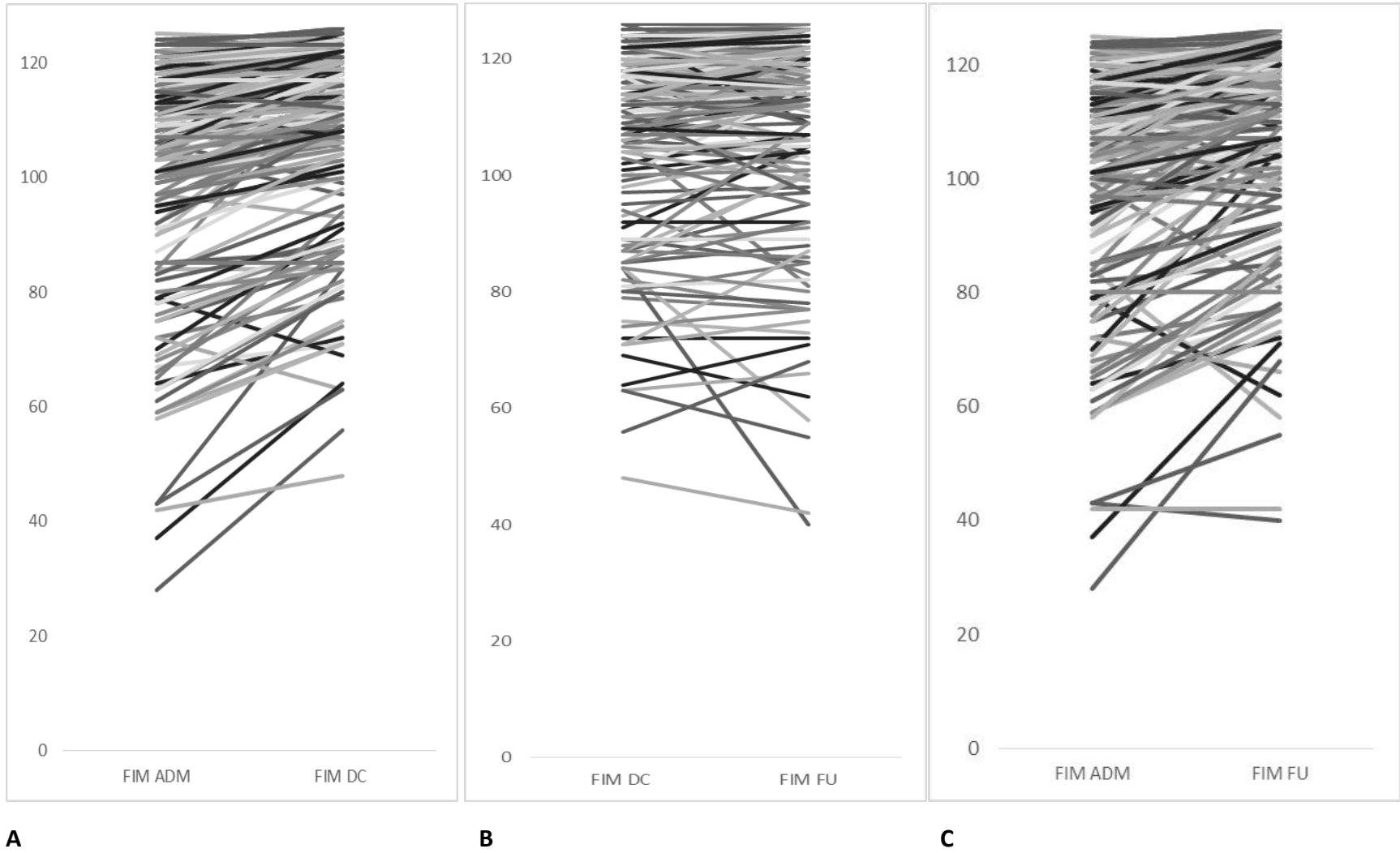


Table 2. Results of one-way repeated measures ANOVA analysis evaluating the Functional Independence Measure (FIM), Reintegration to Normal Living Index (RNLI), and Bakas Caregiving Outcomes Scale (BCOS) across the three time points of admission, discharge, and follow-up.

Outcome Measures	Time 1: Admission	Time 2: Discharge	Time 3: Follow-up	Significance
FIM	103.15 ^A	101.02 ^B	110.38 ^C	p< 0.01
BCOS	37.34 ^A	41.13 ^B	40.12 ^C	p< 0.01
RNLI	15.10 ^A	17.93 ^B	18.61 ^C	p< 0.01

Notes: The superscript letters relate to the results of the post hoc pair-wise evaluation for the variable between time points. Different letters indicate statistical significance between pairs.

The line graphs in Figure 1 demonstrate a ceiling effect within the FIM scores for the sample. For individual FIM scores, 58.5 per cent of scores were above 110 at admission and discharge. The mean FIM score was 101.02 ± 20.44 at discharge and 110.28 ± 15.68 at follow-up with 51.5 per cent of the sample between 116 and 126.

One-way repeated measure ANOVAs demonstrated significant differences for FIM, RNLI and BCOS ($p < 0.001$). Post-hoc pair-wise comparisons indicated statistically significant differences between each time point for the FIM, RNLI and BCOS. All variables demonstrated increased scores from admission to follow-up indicating improvement.

The first set of analyses to address Objective one demonstrated there was no association between functioning and caregiver lifestyle changes across the two time periods of admission to discharge and discharge to follow-up. (See Table 3) The second set of analyses to address Objective one using the absolute and relative FIM change scores demonstrated the following results. (See Table 4) The findings suggest the absolute functional gain between admission and discharge was associated with caregiving scores at admission ($p = 0.01$), discharge ($p = 0.01$), and follow-up ($p = 0.02$). Furthermore, caregivers who demonstrated a

“change for the worst” were associated with increased patient absolute functional gains ($p < 0.05$). Individuals who reported worse caregiving lifestyle changes between admission and discharge from CSRT were associated with an increased percentage of absolute functional gain. Participants who had greater functional gains based on the percentage they changed on FIM scores were associated with worse self-reported BCOS scores. A reduction in relative functional gain was associated with caregiving scores at admission ($p = 0.01$) and the change in caregiving scores from admission to discharge ($p = 0.03$).

The second set of analyses for Objective one demonstrated there was an association between increased BCOS scores and absolute functional efficiency scores from discharge to follow-up ($p = 0.04$). Relative functional efficiency scores, an expression of the total number of points change per day of CSRT stay, were associated with BCOS scores at discharge ($p < 0.05$), follow-up ($p < 0.05$), and the change in caregiving scores from discharge to follow-up ($p = 0.03$). (See Table 5)

The first set of analyses to address Objective two revealed an association between patient reintegration and functioning. This association suggested that as functioning increased patients experienced improved reintegration into normal living. The results from the second set of analyses to address Objective two suggest that increased functioning moderates the relationship between caregiving lifestyle changes and reintegration at between both time periods ($p < 0.001$). There was no association between reintegration and caregiving scores when comparing the variables at admission, discharge and follow-up. (See Table 6)

Furthermore, the results from the third set of analyses to address Objective two suggest that caregivers who reported worse scores on follow-up were associated with patients who showed improvements in functioning. (See Table 7) People with stroke whose caregivers had a “change for the worst” based on the BCOS demonstrated improvements in functioning as measured by the FIM change between admission and discharge. There were significant relationships between functioning and reintegration at all time points. Caregivers who had “did not change” demonstrated a significant association with worse patient reintegration to normal living from discharge to follow-up. (See Table 7)

Table 3. Results of analysis of covariance (ANCOVA) regression modelling of the association between caregiver lifestyle changes on the functional gains in the stroke survivor receiving a community-based rehabilitation program, over two time points: admission to discharge and discharge to follow-up.

Notes: *Adjusted for total visits, intensity, length of stay, age, time since stroke, residence. BCOS 1, Bakas Caregiving Outcomes Scale at admission; BCOS 2,

Dependent Variable	Independent Variable	Unadjusted β (95% CI)	Significance	Adjusted β^* (95% CI)	Significance
FIM2	BCOS 1	0.06 (-0.06-0.19)	p=0.33	0.07 (-0.58-0.20)	p=0.29
FIM2	Δ BCOS 1-2	-0.02 (-0.12-0.08)	p=0.77	-0.02(-0.12-0.79)	p=0.70
FIM3	BCOS 2	0.02 (-0.09-0.12)	p=0.76	0.01(-0.09-0.11)	p=0.84
FIM3	Δ BCOS 2-3	-0.08(-0.02-0.03)	p=0.14	-0.08(-0.18-0.02)	p=0.14

Bakas Caregiving Outcomes Scale at discharge BCOS; Δ BCOS 1-2, Bakas Caregiving Outcome Scale change score between admission and discharge; Δ BCOS 2-3, Bakas Caregiving Outcome Scale change scores between discharge and follow-up; FIM2, Functional Independence Measure at discharge; FIM 3, Functional Independence Measure at follow-up. Significant values denoted by bolding. Statistical significance set at $p < 0.05$.

Table 4. Results of multivariable linear regression modeling to evaluate the association between caregiver lifestyle changes and functioning as quantified using the absolute and relative FIM change scores from admission to discharge from rehabilitation.

Dependent Variable	Independent Variables	Unadjusted β (95% CI)	Significance	Adjusted β^* (95% CI)	Significance
FIM AFG 1	BCOS 1	0.09 (-0.20-0.38)	p =0.52	0.35 (0.08-0.63)	p =0.01
	BCOS 2	0.16 (-0.42-0.36)	p =0.12	0.39 (0.01-0.41)	p =0.01
	Δ BCOS 1-2	-1.91 (-0.42-0.037)	p =0.10	-0.23 (-0.44-0.03)	p =0.02
	Δ BCOS - No Δ BCOS	2.35 (0.01-4.68) 4.64 (0.08-5.41)	p=0.03 p= 0.42	5.40 (1.22-9.57) -0.29 (-6.13-5.53)	p =0.01 p=0.92
FIM AFG % 1	BCOS 1	0.09 (-0.49-0.16)	p =0.29	0.20 (-0.11-0.15)	p =0.16
	BCOS 2	-0.09 (-0.22-0.06)	p =0.28	0.05 (-0.03-0.14)	p =0.22
	Δ BCOS 1-2	-0.10 (-0.16-0.03)	p =0.18	-0.07 (-0.17-0.28)	p =0.76
	Δ BCOS - No Δ BCOS	-1.36 (-3.92-1.20) 1.86 (0.01-3.71)	p =0.30 p<0.05	-1.42 (-8.29-3.41) 2.21 (0.29-3.95)	p =0.43 p =0.02
FIM AFE 1	BCOS 1	0.00 (-0.01-0.01)	p =0.83	0.01 (-0.01-0.04)	p =0.37
	BCOS 2	0.04 (-0.01-0.02)	p =0.56	0.01 (-0.01-0.02)	p =0.57
	Δ BCOS 1-2	-0.01 (-0.03-0.01)	p =0.53	0.01(-0.03-0.01)	p =0.40
FIM RFG 1	BCOS 1	-0.58 (-1.03-0.13)	p =0.01	0.06(-0.28-0.40)	p =0.73
	BCOS 2	0.01 (-0.27-0.32)	p =0.89	0.13(-0.14-0.40)	p =0.34
	Δ BCOS 1-2	0.22 (-0.11-0.54)	p =0.19	-0.28(-0.53-0.02)	p =0.03
FIM RFE 1	BCOS 1	0.16 (-0.08-0.10)	p =0.90	0.01 (-0.01-0.01)	p =0.30
	BCOS 2	0.01 (-0.06-0.09)	p =0.13	0.09 (0.01-0.01)	p =0.26
	Δ BCOS 1-2	-0.71 (-0.05-0.08)	p =0.33	0.01 (0.01-0.01)	p =0.32

Notes: *Adjusted for total visits, intensity, length of stay, age, time since stroke, residence. BCOS 1, Bakas Caregiving Outcomes Scale at admission; BCOS 2, Bakas Caregiving Outcomes Scale at discharge; Δ BCOS 1-2, Bakas Caregiving Outcome Scale change score between admission and discharge; Δ BCOS -, Bakas Caregiving Outcome Scale caregivers who “changed for the worst” between admission and discharge; No Δ BCOS, caregivers who had “did not change” from admission to discharge; FIM RFG 1, Relative functional gain between admission and discharge; FIM AFG 1, Absolute functional gain between admission and discharge; FIM AFG %, Absolute functional gain percentage between admission and discharge; FIM RFE 1, Relative functional efficiency between admission and discharge; FIM AFE 1, Absolute functional efficiency between admission and discharge. Significant values denoted by bolding. Statistical significance set at p<0.05.

Table 5. Results of multivariable linear regression modeling to evaluate the association between caregiver lifestyle changes and functioning as quantified using the absolute and relative FIM change scores from discharge to follow-up from rehabilitation.

Dependent Variable	Independent Variables	Unadjusted β (95% CI)	Significance	Adjusted β^* (95% CI)	Significance
FIM AFG2	BCOS 2	0.02 (-0.08-0.12)	p =0.77	0.02 (-0.08-0.12)	p =0.78
	BCOS 3	0.08 (-0.04-0.21)	p =0.46	0.10 (-0.04-0.25)	p =0.15
	Δ BCOS 2-3	-0.04 (-0.16-0.74)	p =0.18	-0.03 (-0.15-0.09)	p =0.67
	Δ BCOS- 2	1.96 (-0.06-3.98)	p =0.06	1.44 (-0.60-3.49)	p =0.16
	No Δ BCOS 2	2.23 (-0.70-5.17)	p =0.14	2.30 (-0.28-3.91)	p =0.78
FIM AFG% 2	BCOS 2	-0.04(-0.13-0.06)	p =0.46	0.01 (-0.07-0.09)	p =0.78
	BCOS 3	0.10 (-0.01-0.20)	p =0.05	0.07 (-0.03-0.17)	p =0.18
	Δ BCOS 2-3	- 0.06 (-0.15-0.02)	p =0.15	-0.04 (-0.13-0.06)	p =0.46
	Δ BCOS- 2	1.56 (-0.48-3.16)	p =0.06	1.82 (-0.56-4.31)	p =0.63
	No Δ BCOS 2	1.77 (-0.55-4.10)	p =0.14	1.46 (-0.17-3.10)	p =0.07
FIM AFE 2	BCOS 2	-0.04 (-0.19-0.11)	p =0.11	0.15 (-0.03-0.33)	p =0.09
	BCOS 3	0.15 (0.06-0.28)	p =0.04	0.15 (0.00-0.29)	p =0.04
	Δ BCOS 2-3	-0.09 (-0.23-0.04)	p =0.17	-0.02 (-0.17-0.14)	p =0.79
FIM RFE 2	BCOS 2	0.05 (-0.28-0.29)	p<0.05	0.01 (0.01-0.02)	p =0.03
	BCOS 3	-0.12 (-0.22-0.02)	p<0.05	0.01 (-0.01-0.01)	p =0.01
	Δ BCOS 2-3	-0.16 (-0.03-0.01)	p =0.03	-0.15 (-0.01-0.01)	p =0.04
FIM RFG 2	BCOS 2	-0.67(-0.36-0.23)	p =0.97	0.01(-0.01-0.01)	p =0.07
	BCOS 3	-0.07 (-0.34-0.20)	p =0.60	0.02(-0.22-0.27)	p =0.86
	Δ BCOS 2-3	0.03 (-0.22-0.29)	p =0.25	0.15 (-0.08-0.38)	p =0.48

Notes: *Adjusted for total visits, intensity, length of stay, age, time since stroke, residence. BCOS 2, Bakas Caregiving Outcomes Scale at discharge; BCOS 3, Bakas Caregiving Outcomes Scale at follow-up; Δ BCOS 2-3, Bakas Caregiving Outcome Scale change scores between discharge and follow-up; Δ BCOS – 2, Bakas Caregiving Outcome Scale caregivers who “changed for the worst” between discharge to follow-up; No Δ BCOS 2, caregivers who had “did not change” from discharge to follow-up; FIM RFG 2, Relative functional gain between discharge and follow-up; FIM AFG 2, Absolute functional gain between discharge and follow-up; FIM AFG % 2, Absolute functional gain percentage between discharge and follow-up; FIM RFE 2, Relative functional efficiency between discharge and follow-up; FIM AFE 2, Absolute functional efficiency between discharge and follow-up. Significant values denoted by bolding. Statistical significance set at p<0.05.

Table 6. Results of analysis of covariance (ANCOVA) regression modeling between caregiver lifestyle changes and reintegration to normal living in the stroke survivor receiving a community-based rehabilitation program over two time periods: admission to discharge and follow-up from discharge.

Dependent Variable	Independent Variables	Unadjusted β (95% CI)	Significance	Adjusted β^* (95%CI)	Significance
RNLI 2	BCOS 1	0.03 (-0.37-0.90)	p=0.41	0.01 (-0.51-0.080)	p=0.67
RNLI 2	Δ BCOS 1-2	-0.03 (-0.05-0.05)	p=0.89	0.01(-0.50-0.49)	p=0.99
RNLI 3	BCOS 2	0.03 (-0.16-0.07)	p=0.23	0.03 (-0.02-0.07)	p=0.22
RNLI 3	Δ BCOS 2-3	0.08 (-0.35-0.50)	p=0.72	0.09 (-0.03-0.05)	p=0.67
RNLI 2	Δ BCOS 1-2 FIM2	0.10 (0.08-0.13)	p<0.001	0.06 (0.03-0.10)	p<0.001
RNLI 3	Δ BCOS 2-3 FIM 3	0.08 (0.05-0.10)	p<0.001	0.11 (0.08-0.14)	p<0.001

Notes: *Adjusted for total visits, intensity, length of stay, age, time since stroke, residence. BCOS 1 , Bakas Caregiving Outcomes Scale at admission; BCOS 2, discharge; BCOS 3, follow-up; Δ BCOS 1-2, Bakas Caregiving Outcome Scale change score between admission and discharge; Δ BCOS 2-3, Bakas Caregiving Outcome Scale change scores between discharge and follow-up; RNLI 2, Reintegration to Normal Living Index at discharge; RNLI 3, Reintegration to Normal Living Index at follow-up. FIM2, Functional Independence Measure at discharge; FIM 3, Functional Independence Measure at follow-up. Significant values denoted by bolding. Statistical significance set at p<0.05

Table 7. An evaluation of the association between Reintegration to Normal Living Index and computed Bakas Caregiving Outcomes Scale (BCOS) variables: “change for worse” or “did not change” in reference to “positive change” in BCOS over two time periods: admission to discharge and follow-up from discharge.

Dependent Variable	Independent Variables	Unadjusted β (95% CI)	Significance	Adjusted β^* (95% CI)	Significance
RNLI 2	Δ BCOS - No Δ BCOS	-0.03 (-1.71-1.64)	p =0.80	-0.31 (-1.68-1.07)	p =0.48
RNLI 3	Δ BCOS - 2 No Δ BCOS2	-1.42 (-0.97-0.86)	p =0.04	-0.07 (-1.01-0.08)	p =0.04
RNLI 2	Δ BCOS - No Δ BCOS FIM 2	0.10 (0.07-0.96)	p<0.001	0.09 (0.06-0.13)	p<0.001
RNLI 3	Δ BCOS - 2 No Δ BCOS 2 FIM 3	0.11 (0.09-0.14)	p<0.001	0.13 (0.10-0.15)	p<0.001

Notes: *Adjusted for total visits, intensity, length of stay, age, time since stroke, residence. Δ BCOS - , Bakas Caregiving Outcome Scale caregivers who “changed for the worst” between admission and discharge; No Δ BCOS, caregivers who had “did not change” from admission to discharge; Δ BCOS – 2, Bakas Caregiving Outcome Scale caregivers who “changed for the worst” between discharge to follow-up; No Δ BCOS 2, caregivers who had “did not change” from discharge to follow-up; FIM 2, Functional Independence Measure at discharge; FIM 3, Functional Independence Measure at follow-up; RNLI 2, Reintegration to Normal Living Index at discharge; RNLI 3, Reintegration to Normal Living Index at follow-up. Significant values denoted by bolding. Statistical significance set at p<0.05

Chapter 6: Discussion

6.0 Discussion

This study has demonstrated that worsening scores for caregivers over the duration of rehabilitation were associated with patients who showed improvements in function. In addition, caregiver scores that showed no change for better or worse were associated with better patient reintegration. The values for the FIM, BCOS and RNLI all demonstrated increased scores from admission to follow-up indicating improvement over the time frame of the study. The associations between patient reintegration and functioning suggest that as function increases patients' reintegration improves.

The finding of an association between caregiver lifestyle changes on the functional gains in the stroke survivor receiving a community-based rehabilitation program is a novel contribution to the literature. The association was present with the use of relative measures of rehabilitation gain. The FIM is known to have ceiling effects and the sample for this study was very high functioning with the majority having scores near the maximum. The use of standard analytic metrics for change in function was limited in finding change over a very narrow range of scores. This was an important reason for using the relative and absolute functional gain and efficiency scores. The functional efficiency scores account for how much of the difference between admission and the maximal score each person was able to achieve, rather than using raw scores to detect change over time. Functional gain and efficiency scores between admission and discharge were associated with caregiving scores at admission, discharge, and follow-up. Furthermore, caregivers who demonstrated a "change for the worst" were

associated with increased absolute functional gains in stroke survivors. A potential explanation for the finding could be related to the amount of time required to care for a stroke survivor resulting in a negative change for the caregiver. However, the additional care provided by the caregiver was associated with increased functioning in the stroke survivor.

The findings from this study suggest that people with stroke whose caregivers had a “change for the worst” based on the BCOS demonstrated improvements in functioning as measured by the FIM change between admission and discharge. This finding is different from what is currently understood within the stroke survivor and caregiver literature to date. Dankner et al. (2016) found that caregivers’ anxiety levels were higher than that of the survivors and anxiety was the only characteristic of caregivers that was associated with overall caregiver burden. It was believed that there was a spillover effect of anxiety from the stroke patients to the primary caregivers. Slot et al. (2008) reported the mean survival of patients following stroke to differ considerably, from 2.5 to 12.9 years, for low and high functional status assessed at six months. Nevertheless, functional disability was not associated with caregiver burden in that study. Similarly, functional disability was not associated with caregiver burden three months to two years after stroke in a study from India (Sreedharan et al., 2013).

The results from this current study suggest that function significantly improved on transition from rehabilitation discharge to follow-up. Bhogal et al. (2003) conducted a systematic review of the literature evaluating issues facing stroke survivors and their families upon reintegration into the community. The results suggested there was evidence that improved social support for family caregivers as an intervention improves outcomes and had a positive impact on functioning post-stroke. Furthermore, according to the Canadian Stroke Best

Practice Recommendations suggest patients with stroke, family, and caregiver education is an integral part of stroke care that must be addressed at all stages and settings across the continuum of stroke care (Cameron et al., 2016). A retrospective chart review with follow-up telephone interviews of people with severe stroke admitted to an inpatient stroke rehabilitation program found the presence of a caregiver at time of discharge from the inpatient rehabilitation was predictive of significantly higher functional ability (Mirkowski et al., 2016).

Our findings suggest there were significant differences across all time points of admission, discharge, and follow-up for FIM. Similar to the findings in the literature, participants' FIM scores demonstrated increased scores from admission to follow-up indicating improvement. Finally, function in the person with stroke moderates the relationship between caregiver lifestyle change and reintegration into the community for stroke survivors. Timbeck and Spaulding (2003) conducted a literature review to evaluate the ability of the FIM in predicting functional outcomes following a stroke. The parameters they evaluated included functional performance at discharge, length of rehabilitation stay, and discharge destination. They found that the admission FIM score was a strong predictor of discharge FIM score, outcome disability, and discharge destination. Patients with admission FIM scores less than 50 remain dependent with self-care activities at discharge from rehabilitation. Patients with admission FIM scores equal to or greater than 90 were independent with most activities of daily living and had a high likelihood of being discharged home. Furthermore, Wang et al. (2014) conducted a randomized controlled trial with blinded outcome assessment of a home-based

intervention and found that the intervention improved physical functioning and social participation in people with chronic stroke.

6.1 Strengths and Limitations

Strengths of this study include the analysis of a large sample of 200 participants. In addition, the quantification of functional recovery and reintegration in the stroke survivor population with the use of multiple measures derived from the FIM, BCOS and RNLI is unique in the literature. The robust findings using confounders for adjusted analyses addressing both objectives demonstrated an increased strength in beta coefficients. This increase indicated that the adjusted analysis strengthened the association between absolute functional gain and caregiving lifestyle changes as well as the association between caregiver lifestyle changes and reintegration from discharge to admission.

This study's main limitations relate to the influence of residual confounding, such as the level of participation of other services provided to the people with stroke in addition to that provided by the CSRT. Furthermore, the FIM scores at admission were near the maximal score of 126, making the ability to detect change in the FIM over time difficult due to ceiling effects. To overcome this limitation functional gain and efficiency scores were used. Moreover, we cannot be certain about the details of the person identified as the caregiver (for example, son, daughter, spouse or if the caregiver resided with the person with the stroke or not). Another limitation of our study relates to the retrospective cohort study design, specifically the question and variables of interest are constrained by information already collected in the dataset. A limitation of the BCOS is no defined reference point (such as 24 hours), therefore a comparison

of lifestyle change prior to the survivors' stroke could be subject to recall bias from the caregiver.

6.2 Future Direction

A potential stream for future research should account for who the caregiver is at all time points as this may have a relevant impact on the caregiver experience. In addition, information related to how much time the caregivers spend with the stroke survivors each day would be very valuable. Future studies should also consider the functional status of the caregiver, identify the caregivers' relationship to the person with the stroke (e.g., son, daughter, or spouse) and whether the caregiver is directly providing care services and what those services are over time. Moreover, it is important to note if there is a change in residence for the person with the stroke from admission to discharge from rehabilitation. A residence change can be used to evaluate how living environment may influence functional recovery patterns. Future studies would also need to account for the other services to which the stroke survivor may be receiving once they return to the community if research was conducted again within a CSRT model. Importantly, access to rehabilitation services in rural versus urban centres is known to be different and this may directly impact the caregiver/stroke survivor relationship. The services within rural and urban centers and the additional travel needed to access these services from remote areas should be evaluated.

Chapter 7: Conclusion

Literature has shown that functional disability of the person with the stroke has not been associated with caregiver burden during the time frame of three months to two years after stroke (Sreedharan et al., 2013). However, there was an association between well-being of both stroke survivors and caregivers, the survivors' characteristics, and caregiver burden (Dankner et al., 2016). Furthermore, home-based rehabilitation interventions improve physical functioning and social participation in people with chronic stroke (Wang et al., 2014) and the presence of a caregiver at the time of discharge from inpatient rehabilitation is predictive of significantly higher functional ability at discharge in individuals with severe stroke (Mirkowski et al., 2016).

The findings of this study suggest that the associations between patient reintegration and functioning are related such that as function increases patients' reintegration improves. Additionally, the results suggest that, worsening lifestyle scores in caregivers over the duration of rehabilitation were associated with patients who showed improvements in function. In addition, caregiver scores that showed no change were associated with better patient reintegration admission to follow-up. Patients in a CSRT program with a caregiver showed increased scores for FIM, RNLI, and BCOS from admission to follow-up indicating improvement.

Future studies need to account for whom the caregiver is in relation to the patient at all time points. In addition, the amount of time caregivers spend with the stroke survivors and the overall impact this time has on patient function would be valuable relationship to explore. The change in functional status of the caregiver in providing care would also be interesting to

analyze. The impact of the residence of the stroke survivor before and after the initial stroke should be evaluated, in addition to the assessment of distance and access to care services within the community following discharge.

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Appendix 1. Ethical Approval



Research Ethics

Western University Health Science Research Ethics Board HSREB Annual Continuing Ethics Approval Notice

Date:

Principal Investigator: Dr. Robert Teasell

Department & Institution: Schulich School of Medicine and Dentistry/Physical Medicine & Rehab, St. Joseph's Health Care London

Review Type: Expedited

HSREB File Number: 102728

Study Title: Community Stroke Rehabilitation Team Database: An Analysis of the Data

Sponsor:

HSREB Renewal Due Date & HSREB Expiry Date:

Renewal Due -2017/06/30

Expiry Date -2017/07/05

The Western University Health Science Research Ethics Board (HSREB) has reviewed the Continuing Ethics Review (CER) Form and is re-issuing approval for the above noted study.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice (ICH E6 R1), the Ontario Freedom of Information and Protection of Privacy Act (FIPPA, 1990), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

Ethics Officer: Erika Basile ___ Katelyn Harris ___ Nicole Kanaki ___ Grace Kelly ___ Vikki Tran ___ Karen Gopaul ✓

Appendix 2. Bakas Caregiving Outcomes Scale (BCOS)

As A Result of Providing Care for the Patient:	Changed for the worst.			Did not change	Changed for the best.		
	-3	-2	-1		0	+1	+2
1. My self esteem	-3	-2	-1	0	+1	+2	+3
2. My physical health	-3	-2	-1	0	+1	+2	+3
3. My time for family activities	-3	-2	-1	0	+1	+2	+3
4. My ability to cope with stress	-3	-2	-1	0	+1	+2	+3
5. My relationship with friends	-3	-2	-1	0	+1	+2	+3
6. My future outlook	-3	-2	-1	0	+1	+2	+3
7. My ability to pay the bills	-3	-2	-1	0	+1	+2	+3
8. My emotional well-being	-3	-2	-1	0	+1	+2	+3
9. My time for social activities with friends	-3	-2	-1	0	+1	+2	+3
10. My relationship with my family.	-3	-2	-1	0	+1	+2	+3
11. My ability to buy necessities.	-3	-2	-1	0	+1	+2	+3
12. My relationship with the patient.	-3	-2	-1	0	+1	+2	+3
13. In general, how has your life changed as a result of taking care of the patient?	-3	-2	-1	0	+1	+2	+3
Are there any other changes in your life that you experiences from providing care for the patient? If so please write them below and rate them accordingly.	Changed for the worst.			Did not change	Changed for the best.		
14.	-3	-2	-1		0	+1	+2
15.	-3	-2	-1	0	+1	+2	+3
16.	-3	-2	-1	0	+1	+2	+3

Appendix 3. Functional Independence Measure (FIM)

	ADMISSION	DISCHARGE	FOLLOW-UP
Self-Care			
A. Eating			
B. Grooming			
C. Bathing			
D. Dressing - Upper Body			
E. Dressing - Lower Body			
F. Toileting			
Sphincter Control			
G. Bladder Management			
H. Bowel Management			
Transfers			
I. Bed, Chair, Wheelchair			
J. Toilet			
K. Tub, Shower			
Locomotion			
L. Walk/Wheelchair			
M. Stairs			
<i>Motor Subtotal Score</i>			
Communication			
N. Comprehension			
O. Expression			
Social Cognition			
P. Social Interaction			
Q. Problem Solving			
R. Memory			
<i>Cognitive Subtotal Score</i>			
TOTAL FIM Score			

L E V E L S	Independent 7 Complete Independence (Timely, Safely) 6 Modified Independence (Device)	NO HELPER
	Modified Dependence 5 Supervision (Subject = 100%+) 4 Minimal Assist (Subject = 75%+) 3 Moderate Assist (Subject = 50%+)	HELPER
	Complete Dependence 2 Maximal Assist (Subject = 25%+) 1 Total Assist (Subject = less than 25%)	
Note: Leave no blanks. Enter 1 if patient is not testable due to risk.		

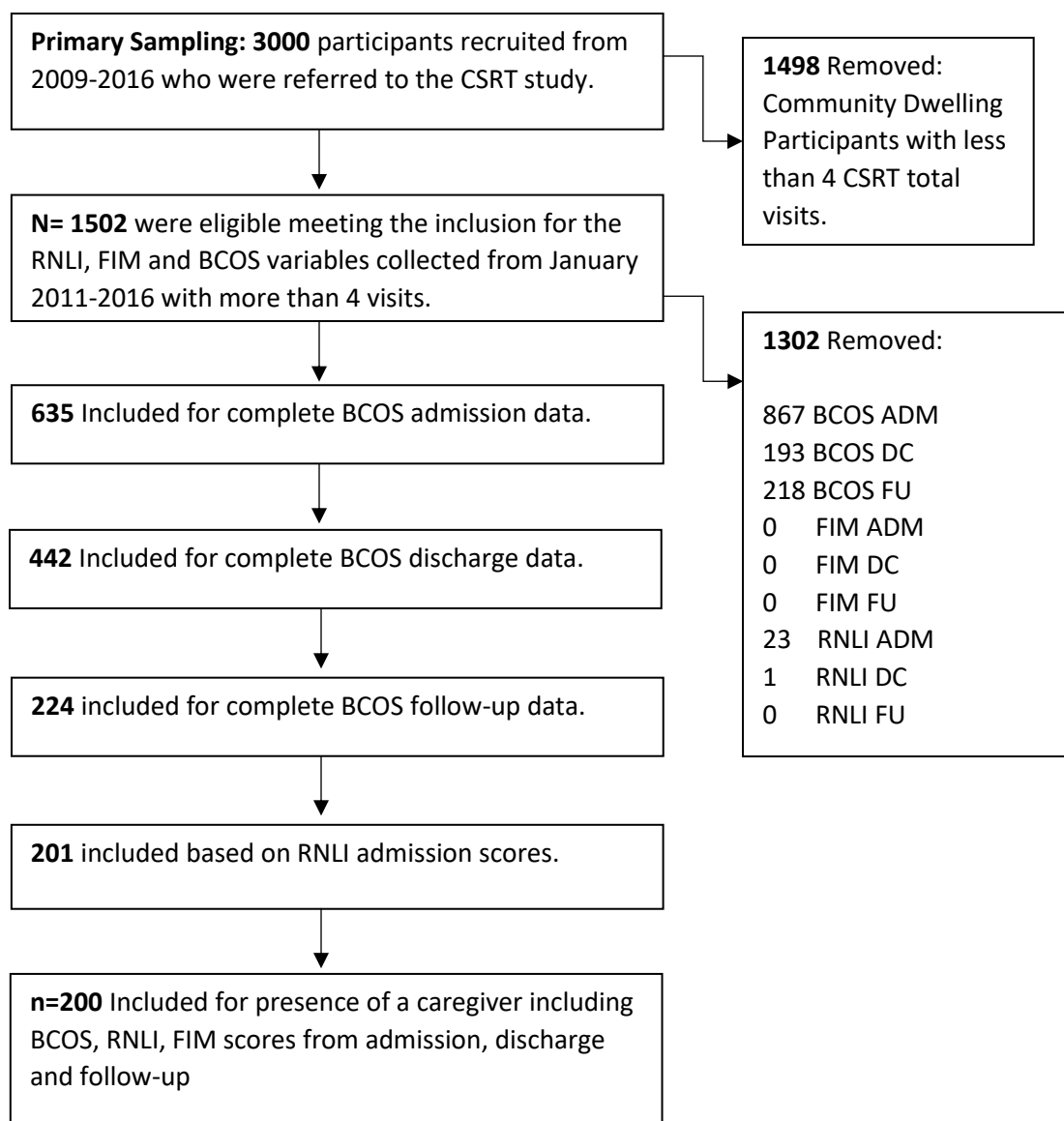
Appendix 4. Reintegration to Normal Living Index (RNLI)

Reintegration to Normal Living Index (RNLI)

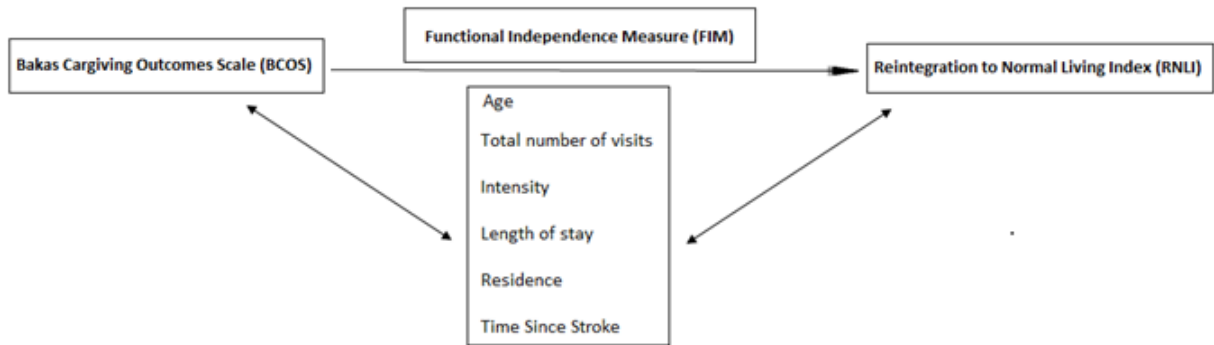
Statements	Does not describe my situation 0	Sometimes describes my situation 1	Always describes my situation 2
I move around my living quarters as I feel is necessary (wheelchair, other equipment or resources may be used).			
I move around my community as I feel necessary (wheelchairs, other equipment or resources may be used).			
I am able to take trips out of town as I feel are necessary (wheelchairs, other equipment or resources may be used).			
I am comfortable with how my self-care needs (dressing, feeding, toileting, bathing) are met (adaptive equipment, supervision and /or assistance may be used).			
I spend most of my days occupied in a work activity that is necessary or important to me (could be paid employment, housework, volunteer work, school, etc., adaptive equipment, supervision and / or assistance may be used).			
I am able to participate in recreational activities (hobbies, crafts, sports, reading, television, games, computers etc.) as I want to (adaptive equipment, supervision and / or assistance may be used).			
I participate in social activities with family, friends, and / or business acquaintances as is necessary or desirable to me (adaptive equipment, supervision and / or assistance may be used).			
I assume a role in my family which meets my needs and those of other family members (family means people with whom you live and / or relatives with who you don't live but see on a regular basis, adaptive equipment, supervision and / or assistance may be used).			
In general I am comfortable with my personal relationships.			
In general I am comfortable with myself when I am in the company of others.			
I feel that I can deal with life events as they happen.			
Total (Add up and add across columns- score 0-22)			

= ___/22

Appendix 5. Flow Chart Overview for generation of data set used for study n=200



Appendix 6. Conceptual Model



Note: The conceptual model was used to theoretically sketch out possible confounders in the exposure/outcome relationship of interest. The line between BCOS and RNLI depicts the association between them with FIM sitting as a moderator on the causal pathway. The variables listed below were identified as confounders and used within the adjusted regression analysis.

Appendix 7. Scatterplots

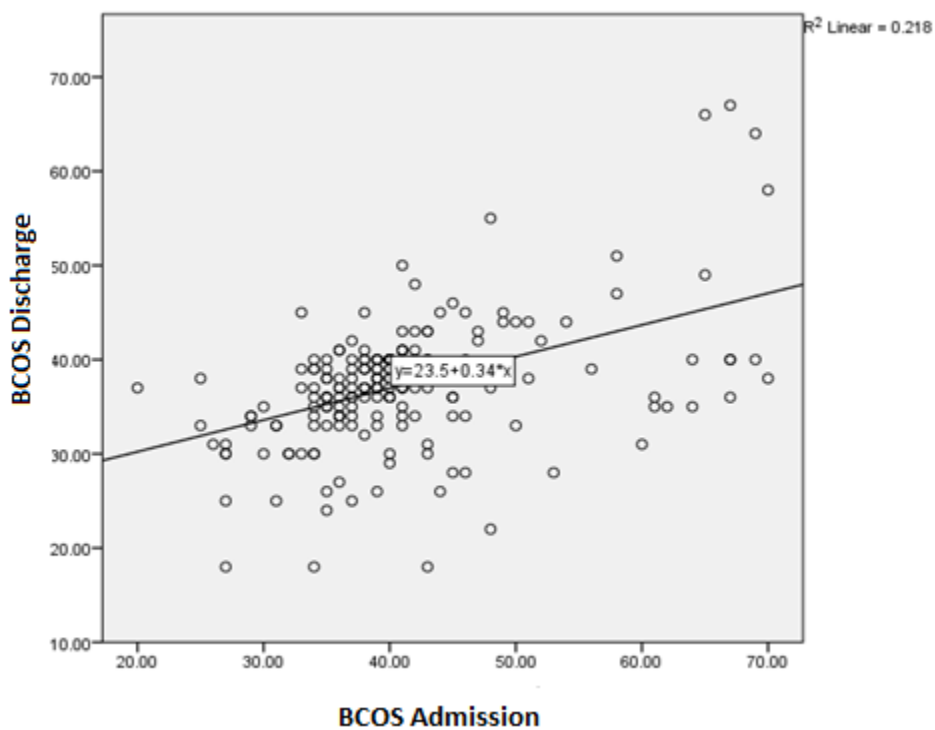


Figure 7a. Scatterplot for Bakas Caregiving Outcomes Scale from Admission to Discharge.

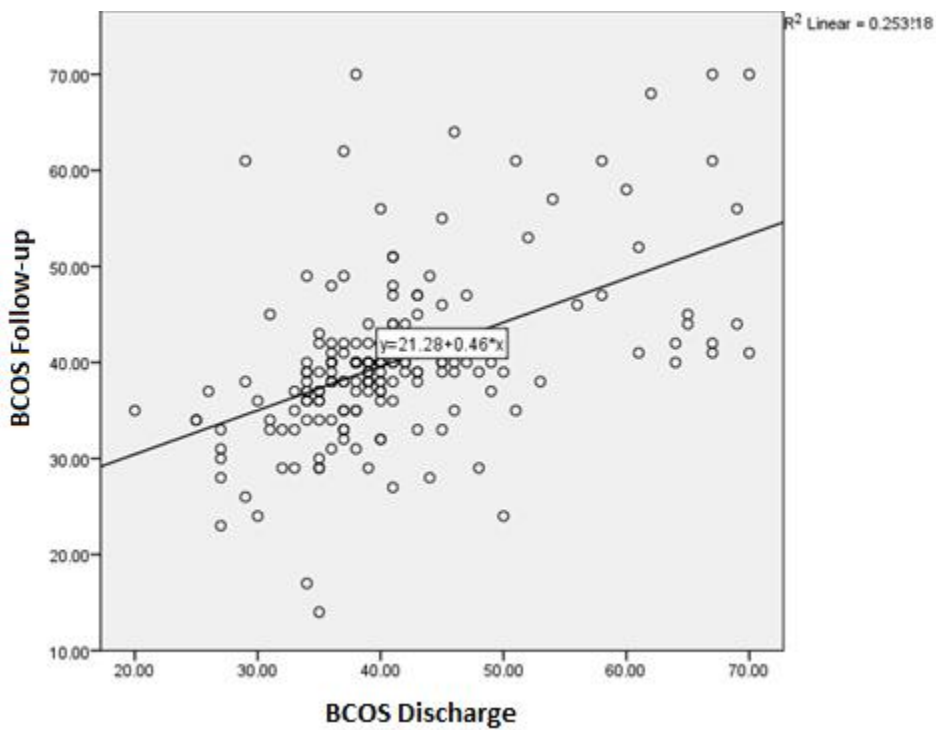


Figure 7b. Scatterplot for Bakas Caregiving Outcomes Scale from Discharge to Follow-up.

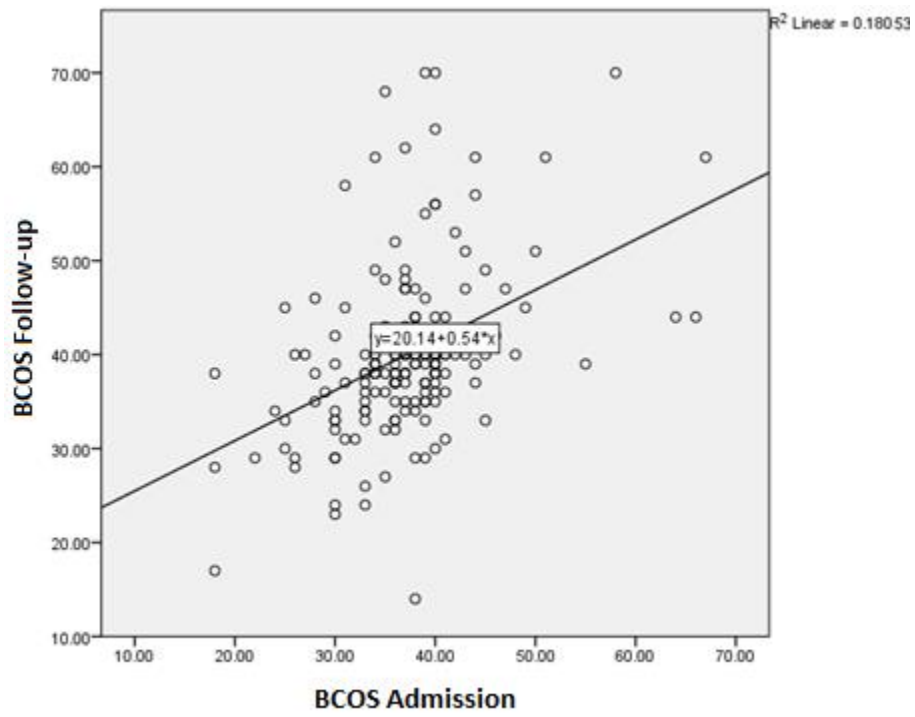


Figure 7c. Scatterplot for Bakas Caregiving Outcomes Scale from Admission to Follow-up.

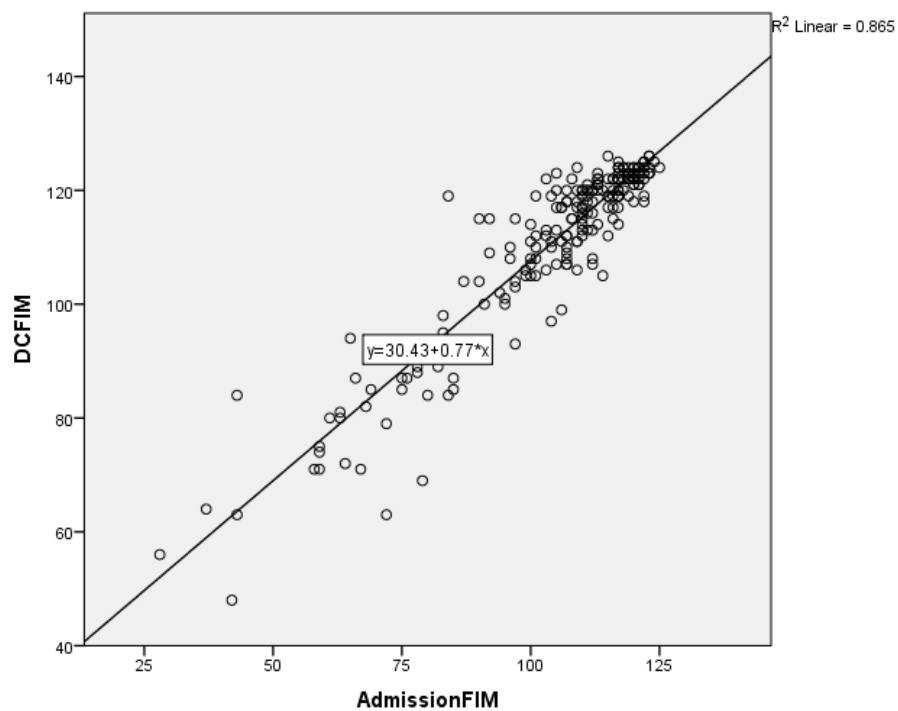


Figure 7d. Scatterplot for Functional Independence Measure from Admission to Discharge.

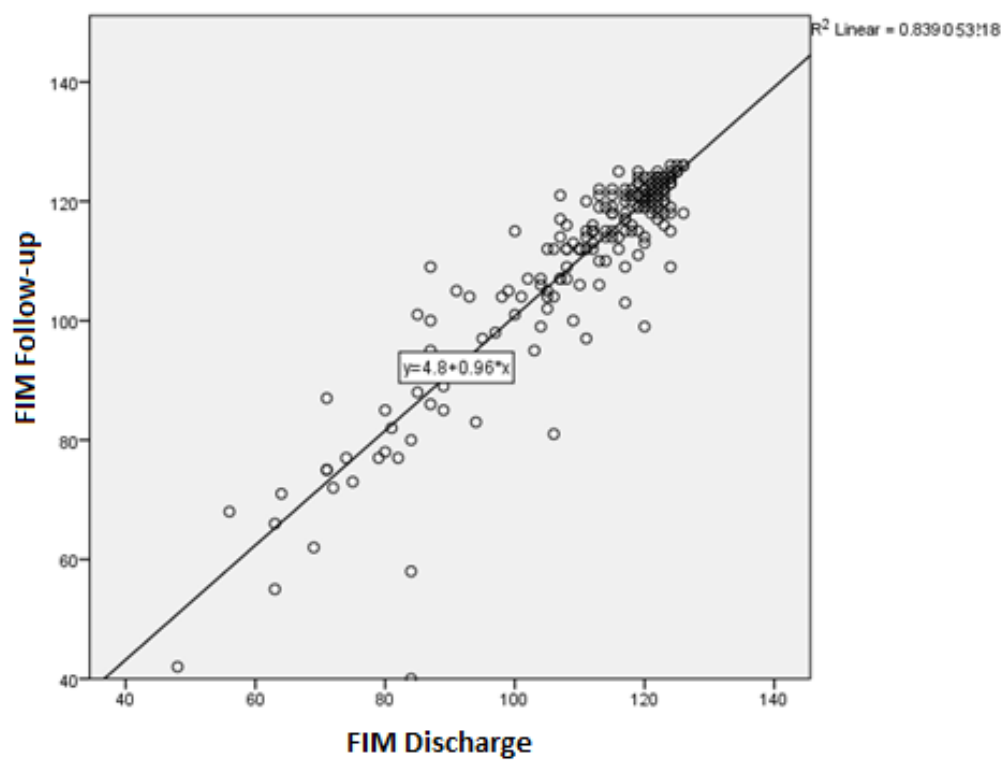


Figure 7e. Scatterplot for Functional Independence Measure from Discharge to Follow-up.

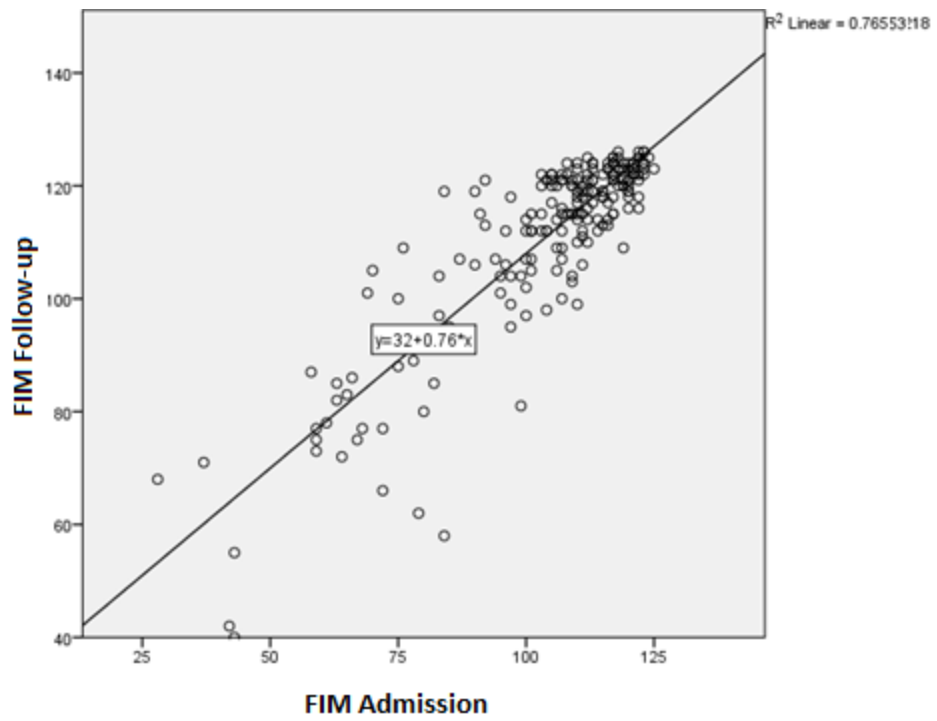


Figure 7f. Scatterplot for Functional Independence Measure from Admission to Follow-up.

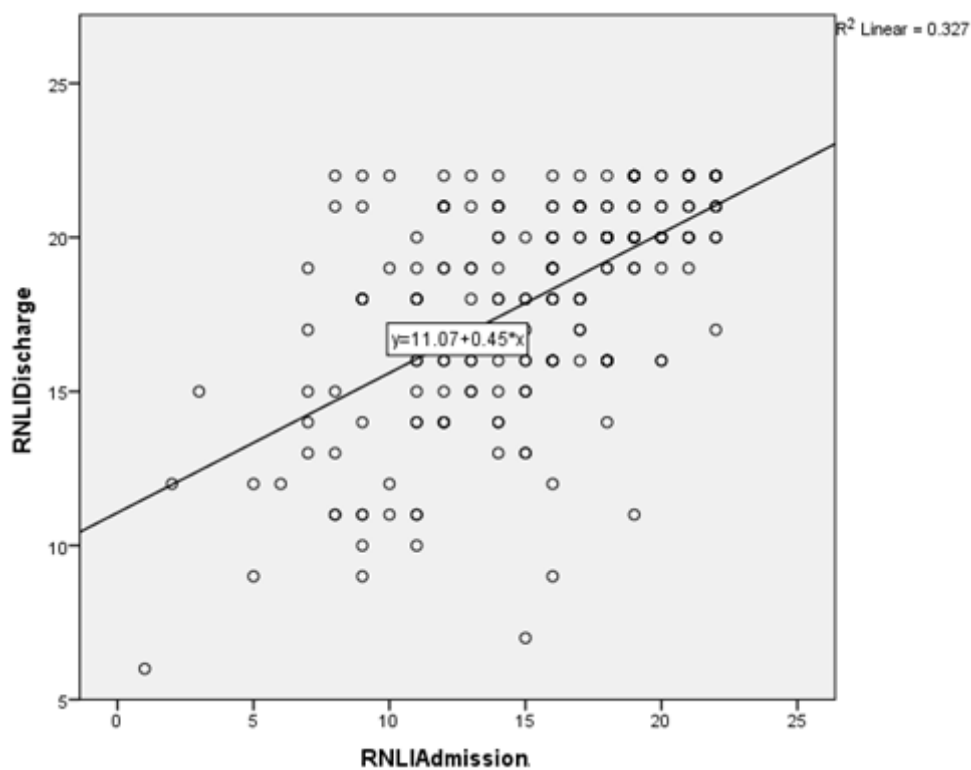


Figure 7g. Scatterplot Reintegration to Normal Living Index from Admission to Discharge.

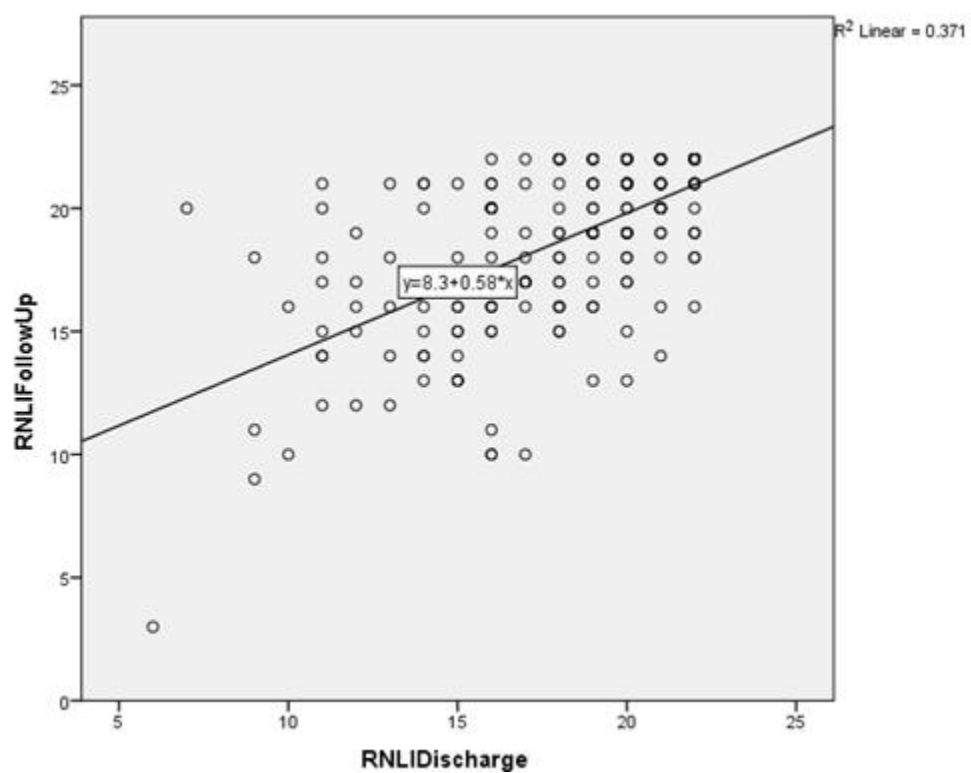


Figure 7h. Scatterplot Reintegration to Normal Living Index from Discharge to Follow-up.

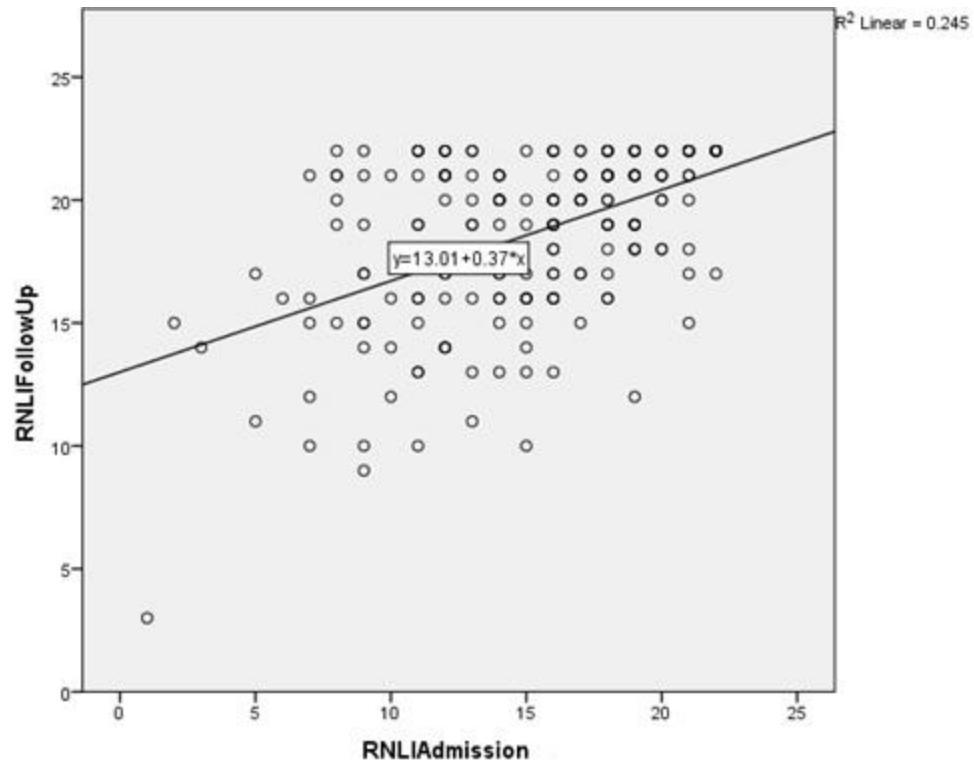


Figure 7i. Scatterplot Reintegration to Normal Living Index from Admission to Follow-up.

Appendix 8. Curriculum Vitae

Name:	Spencer R. Thompson
Post-secondary Education and Degrees:	University of Waterloo Waterloo, Ontario, Canada Honours Bachelor of Science Degree, Health Studies 2009-2013
Honours and Awards:	Canadian Association of Physical Medicine & Rehabilitation (CAPM&R) Honorable Mention 2016 Stroke Interdisciplinary Special Interest Group (ISIG) 2 nd Place Award Winner at American Congress of Rehabilitation Medicine Conference 2015 University of Western Ontario, Graduate Research Scholarship 2015-2017 DarLex Medical Award, Scholarship, University of Waterloo 2009-2013 Health Studies Entrance Scholarship, University of Waterloo 2009
Related Work Experience:	Research Assistant <i>Wii N Walk Study. Lawson Health Research Institute, Parkwood Institute, SJHC, London, ON</i> January 2015-Current Teaching Assistant <i>Health and Rehabilitation Sciences, Physical Therapy, Western University, London, ON</i> September-December 2015, September- December 2016

Research Assistant

CORRE Research Group. Lawson Health Research Institute, Parkwood Institute, SJHC, London, ON

January 2014- September 2015

Research Assistant

School of Public Health and Health Systems, University of Waterloo, Waterloo, ON

August 2013- January 2014

Tutor

Frontier College, Waterloo, ON

September 2012- April 2013

Publications:**Manuscripts**

McIntyre A, **Thompson S**, Burhan A, Mehta S, Teasell R. Treatment of depression due to cerebrovascular disease with repetitive transcranial magnetic stimulation: A systematic review. *Journal of Stroke and Cerebrovascular Disease*. August 2016.

Abstracts

Rice D, Janzen S, McIntyre A, Vermeer J, **Thompson S**, Britt E, Teasell R. Comprehensive outpatient rehabilitation program: A hospital-based stroke outpatient rehabilitation program. GTA Rehab: Best Practices Day. Toronto, ON. 2016.

Bishop K, **Thompson S**, Viana R, Payne M. Rehabilitation Following Lower Limb Amputations in the oldest-old: a scoping review. *Journal of Rehabilitation Medicine* 2016.

Thompson S, Rice D, McIntyre A, Richardson M, Teasell R. Complementary and alternative medicine in stroke rehabilitation. *Archives of Physical Medicine and Rehabilitation* 2015; 96(10):e117.

Thompson S, McIntyre A, Burhan AM, Mehta S, Janzen S, Teasell R. Treatment of vascular depression and post stroke depression using repetitive transcranial magnetic

stimulation: Systematic Review. *Archives of Physical Medicine and Rehabilitation* 2015; 96(10).

McIntyre A, **Thompson S**, Mirkowski M, Burhan A, Miller T, Teasell R. The use of repetitive transcranial magnetic stimulation for spasticity post stroke. *Archives of Physical Medicine and Rehabilitation* 2015; 96(10):e118.

Thompson S, Richardson M, McIntyre A, Orenczuk B, Welch-West P, Viana R. Stroke and Acquired Brain Injury Rehabilitation: Management of Dysphagia and Nutritional Disorders. 2014. *Archives of Physical Medicine and Rehabilitation*, 2015:95, (10), e27.

Thompson S, Macaluso S, Viana R, Payne M, McIntyre A, Teasell R. Long-term Management of Lower Extremity Dysfunction after Stroke. *Journal of Rehabilitation Medicine* 2015.