Developing and evaluating an integrated rehabilitative model of care for stroke patients in the home and community care sector

by

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Author's Declaration

I herby declare that I am the sole author of this thesis. This is a true copy of the thesis,

including any required final versions, as accepted by my examiners.

I understand that my thesis may be made electrincally available to the public.

Abstract

Background: Stroke is a leading cause of disability and the third leading cause of mortality in Canada. Access to evidence-based rehabilitative care can reduce the risk of disability and improve health outcomes of stroke survivors. Up until recently, stroke survivors in many health regions in Canada did not have access to intensive and timely community-based rehabilitation which followed the recommended Canadian Stroke best practice guidelines. As a result, stroke survivors suffered negative health outcomes and had suboptimal experiences as they transitioned to home from a hospital or a rehabilitation centre. The Waterloo Wellington health region of Ontario re-designed its stroke care system across the continuum of care, including implementation of an integrated community stroke rehabilitation pathway that is in alignment with the Canadian stroke best practices. Significant investments in resources have been made to reorganize and integrate the stroke care system with the intention of improving patient outcomes and patient experience. This study aimed to evaluate the newly implemented model of care by measuring patient's health outcomes as well as patient experience. The study also compared the psychometric properties of the interResident Assessment Instrument-Home Care (interRAI HC) with other commonly used assessment tools in the stroke rehabilitation population.

Research Objectives: This research study consisted of two primary research questions and a third secondary question. The first research objective was to answer the question, "What are the functional and depression related outcomes of stroke survivors that received stroke rehabilitation through the community stroke rehabilitation model of care?

The second research objective is to answer the question, "What is the experience of stroke survivors that received care through the community stroke rehabilitation model of care?"

The third research objective aims to answer the question, "How do the psychometric properties of responsiveness and construct validity of specific scales embedded in interRAI HC instrument compare with those of the Barthel Index (BI) and Reintegration to Normal Living Index (RNLI) instruments?"

Methods: To evaluate functional and depression related outcomes, an observational study with a pre-post design was used. Secondary home care data were extracted on patient assessments during April 2014 to April 2017 using the interRAI HC, BI and RNLI instruments. Outcomes were measured for the ADL and DRS scales. A control group was formed using data from the Canadian Institute for Health Information (CIHI); this group included stroke survivors who received traditional rehabilitative care or no care post hospital discharge in the community elsewhere in Ontario during the same period. Four regression models were created to explore associations between having functional or depression related impairment and the treatment assignment (treatment vs control group). Models were adjusted using a propensity score variable to control for treatment selection bias.

To evaluate patient experience, a Patient Experience Survey for Community-based Rehabilitation (PESCR) instrument was developed for this project using a Program Logic

Model (PLM) and also through consultations with subject matter experts and stroke survivors. The PESCR was administered in a home care setting to stroke survivors who completed the rehabilitation program, at the 3 months follow up home visit by a community care coordinator. Participants were asked to provide feedback on: 1) patient experience; 2) transitional care; 3) timeliness of access to care; 4) integrated care; and 5) returning to normal activities. Internal consistency reliability was measured using Cronbach's alpha coefficient. Construct validity was assessed using the correlation of total scores with a global question. Thematic content analysis was used to review the open-ended responses on the survey.

To answer the third research question, responsiveness statistics (standardized response mean and effect size) were used to compare the interRAI HC ADL Long Form and DRS with the BI and RNLI respectively. Construct validity was assessed by the correlation between the ADL Long Form and the BI as well as the correlation between the DRS and the RNLI.

Results

During the period of 2014 and 2017, 479 stroke survivors were placed onto the community stroke rehabilitation pathway for approximately 12 weeks in the Waterloo Wellington health region. Each stroke survivor received an average of 30.5 rehabilitation home visits with an average time of 56 minutes per visit. The mean age of participants was 77.9 (9.5 SD) and 51.2% were females. After adjusting for baseline characteristics and treatment selection bias, participants in the treatment group were three (2.99) times more likely to be

independent in ADLs than those in the control group at the 3 months follow up (Adjusted OR = 2.99, 95% CI 1.53 – 5.86, p < 0.01). Participants in the treatment group were 3.8 times more likely to have no difficulty in IADL activities than those in the control group at the 3 months follow up (Adjusted OR = 3.83, 95% CI 1.77 – 8.25, p < 0.001). There was no statistically significant association found between treatment assignment and depression (Adjusted OR = 0.81, 95% CI 0.47 – 1.38, p > 0.05).

Four hundred and four (84.3%) individuals that received care through the Waterloo Wellington's stroke rehabilitation model of care were asked to complete the patient experience survey. Of these, 134 (33.1%) participants responded including 112 (83.5%) stroke survivors and 22 (16.4%) family members/care givers. Of those that completed the survey, 122 (91.0%) participants were satisfied with the care they received in the community. Based on the open-ended responses, many participants felt that the therapy should have continued beyond the 3-month period post hospital discharge. The responses also suggested that clients and families preferred a longer but less intense physical therapy. Some respondents also felt overwhelmed when the community rehabilitation was initiated within 48 hours of hospital discharge. Some respondents felt that community rehabilitation started too early as stroke survivors and families needed time for adjustment as they transitioned back home.

The interRAI HC's ADL Long Form scale and BI were highly correlated and seem to be evaluating their intended constructs. However, the ADL Long Form was not as responsive as the BI particularly in the subpopulation of stroke population with no or minimal levels

of impairment in conducting ADLs. The DRS and RNLI were not correlated with each other and appear to measure different aspects of an individual's psychosocial outcomes.

The responsiveness results of our study suggest that the ADL and DRS scales from the interRAI HC instrument perform well in subpopulations with significant impairment, such as those who scored high on ADL scales, but these scales have less discriminatory power among those with less physical or psychosocial impairment, such as those with scores of zero on ADL or DRS scales.

Conclusion: Our study adds to the body of evidence suggesting that a community-based rehabilitation program that is timely, well-coordinated and follows the recommended intensity (2-3 rehabilitation visits per week per discipline for up to 12 weeks), can achieve significant improvements in functional outcomes among a large proportion of stroke survivors who are trying to reintegrate back in the community.

The participants had a positive experience overall as well as for specific aspects of care delivery. The lower scores in returning to normal activities suggest that some participants might continue to have unmet needs of functional independence.

The interRAIHC's ADL Long form and the DRS are valuable scales that are already part of the existing bundle of standardized geriatric assessment in the home and community

care. Information collected using these assessments can be useful in the stroke rehabilitation population.

Significance and Knowledge Translation: This study helps establish evidence for whether investments made in stroke community rehabilitative care in the Waterloo Wellington community are resulting in intended patient outcomes and improved patient experience. Results from this study highlight improvement opportunities for the existing model. It is hoped that this study also helps health planners and service providers to implement similar service delivery models in other regions.

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Dedication

I dedicate my dissertation work to my family, my daughers Liyana and Elinor, who have

been the source of my inspirtation and strength throughout this process.

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List of Abbreviations

ADL	Activities of Daily Living
ALC	Alternate Levels of Care
BI	Barthel Index
CCAC	Community Care Access Centre
CCC	Complex Continuing Care
CI	Confidence Interval
CIHI	Canadian Institute for Health Information
CSN	Canadian Stroke Network
DRS	Depression Rating Scale
ES	Effect Size
FIM	Functional Independence Measure
LHIN	Local Health Integration Network
LoS	Length of Stay
OSN	Ontario Stroke Network
OT	Occupational Therapist
PHAC	Public Health Agency of Canada
PESCR	Patient Experience Survey for Community based Rehabilitation
PARIHS	Promoting Action on Research Implementation in Health Services
PT	Physiotherapist
RAI HC	Resident Assessment Instrument - Home Care
RNLI	Reintegration to Normal Living Index
SLP	Speech Language Pathologist
SRM	Standardized Response Mean
WHO	World Health Organization
WW	Waterloo Wellington
WWLHIN	Waterloo Wellington Local Health Integration Network

Chapter 1

Overview

Stroke is a leading cause of adult disability and the third leading cause of death in Canada (1). There are 50,000 strokes (one every 10 minutes) in Canada each year (2). Data from the Canadian Institute for Health Information (CIHI) suggest that between one-third and two-thirds of individuals with stroke will have a loss of function in physical, cognitive or communication skills and will require rehabilitation (3).

Access to rehabilitative care based on best-practices can achieve a reduced risk of death and severe disability, improved functional capacity and improved quality of life for both the stroke survivors and their families (4, 5). Despite the evidence of benefits of rehabilitation for stroke survivors (further described in Chapter 2 in more detail), many developed countries including Canada need improvements in the stroke rehabilitation care system to minimize post stroke disability and improve re-integration to normal living (6-8). In many cases of stroke, the rehabilitation process begins in the hospital or an inpatient rehabilitation setting and continues in the community (6). There are many gaps that exist in the current stroke rehabilitation system with regards to using the recommended stroke best practices (9). In particular, the gaps in the home and community care sector are quite significant (9). Evidence suggests that this sector has not been adequately resourced to meet the needs of the majority of stroke survivors who require rehabilitation (9, 10).

In Canada, not enough people have access to rehabilitation either in the hospital or in the community (6). Only 16% of stroke survivors receive inpatient rehabilitation whereas this number should be around 40% based on outcomes and needs (6). Many studies have reported unmet rehabilitation needs of stroke survivors in the community (11, 12). Of all the stroke survivors that return home, only 11% have access to organized home care support (6) whereas research has suggested that approximately 33% to 43% of stroke survivors need on-going rehabilitation support in the community post discharge (13). Of those that do receive organized home care support for stroke rehabilitation, stroke survivors do not receive the recommended levels of rehabilitation that are aligned with the Canadian best practices (9).

The Canadian stroke best practice guidelines recommend that appropriate patients (refer to section 2.3 for more information on stroke patient groups) should continue to receive rehabilitation (2 -3 visits per week per professional discipline for up to 12 weeks) either in an outpatient setting or in-home after their discharge from an acute care or an inpatient rehabilitation site (9, 14). However, most outpatient rehabilitation facilities in Ontario do not have adequate resources to meet the demand for recommended rehabilitation guidelines (2). Similarly, in the home & community care sector, stroke patients received only an average of 3.9 home visits in total highlighting a significant gap in the community-based stroke care system (9). Although, community-based rehabilitation is a critical component of a best-practice rehabilitation system, inadequate resources due to fiscal constraints and a lack of organized service planning limits the ability to provide best-practice rehabilitation services (9).

For stroke survivors, the initial survival is dependent on the acute phase of specialist hospital stroke care but the greatest impact on the survivor's health and well-being as well as on the cost to society is from the long-term consequences faced after leaving a hospital (15, 16). The gaps in the stroke rehabilitative care system have implications as they may result in poor patient outcomes and a suboptimal patient experience for stroke survivors (4, 17). Other factors that lead to a suboptimal patient experience are a lack of information sharing among community service providers and the added burden of multiple health assessments on front-line health resources (18, 19).

In light of these gaps, the health region of Waterloo Wellington in Ontario redesigned the stroke care system across all sectors, including the home & community care sector (20). The system was re-designed and new models of stroke care were implemented across the continuum of care (20). In particular, a community model of stroke care was developed and implemented that was integrated with the broader local stroke care system, providing rehabilitation services according to the recommended best practices (21). The integrated community rehabilitation model of stroke care is expected to improve patient outcomes and experiences of the stroke survivors that receive services under the new model (21).

This research study aims to evaluate the new community stroke model of care by measuring patient outcomes and patient experience. In addition, the research study evaluates assessment instruments for psychometric properties including responsiveness and construct validity to optimize front-line health resources. In the following sections of this

thesis, a review of the literature (Chapter 2) has been provided on stroke rehabilitation care, the stroke care system in Canada, the home and community care sector, and how the current system impacts patient experience. In addition, a comprehensive summary of new models of care (Chapter 3) across the different health sectors has been provided.

The research questions and the rationale of this study are described in Chapter 4. This chapter also underlines the importance of this study and its contribution to the stroke rehabilitative care literature. It is hoped that the results of this research study will not only help improve the existing model of care but also inform scaling of this model to other communities in Ontario and Canada.

Chapter 5 of this thesis outlines the methods used to answer our research questions.

The knowledge translation and dissemination plan is described in Chapter 6. Results of evaluating the community stroke rehabilitation model are provided in Chapter 7, including results on patient outcomes, patient experience and a psychometric comparison of assessment instruments used in the stroke community rehabilitation population. Implication of our results as well as limitations, strengths and weaknesses are described in Chapter 8. The thesis is concluded with final remarks in Chapter 9.

Chapter 2

Background and Literature Review

2.1 Stroke

The Public Health Agency of Canada (PHAC) defines stroke as a sudden loss of brain function caused by either a blockage (ischemic) or rupture (hemorrhagic) of blood vessels in the brain (1). Weakness or lack of sensation, often on one side of the body, difficulty in speech and vision, headache or loss of coordination and balance are the most common symptoms associated with stroke. Such symptoms or consequent complications of a stroke could potentially impact quality of life. Risk factors associated with stroke can be grouped under non-modifiable (age, sex) and modifiable categories (hypertension, health weight, diet, regular exercise, smoking and blood cholesterol) (1).

According to the World Health Organization (WHO), stroke is a leading cause of disability worldwide in adults. Currently, there are approximately 650 million people at the age of 60 and older. This figure is expected to reach 2 billion by 2050. Twenty-three million first-time strokes and 7.8 million stroke deaths are estimated to occur by 2030 (7). While there has been a decline of stroke incidence in high-income countries, low-middle income countries have experienced a greater than 100% increase in stroke incidence in the last four decades (7).

Stroke can have an impact on the body's function, activities, and participation. Such impact is not only devastating for stroke survivors but also multifaceted as the consequences of stroke are shaped by environmental and personal factors (16). Stroke can cause disability in motor-related impairment, affecting mobility and dexterity. It can also cause impairment in speech and language, swallowing, vision, sensation, and cognition. Such impairments have an effect on an individual's ability to perform everyday activities and to participate in everyday life (22).

2.2 Stroke Rehabilitation

Recent studies have shown that the advancements of hyperacute (i.e., treatment within 6 hours of stroke onset) and acute treatments have resulted in reduced disability for stroke patients (14). Timely access to treatments such as diffusion magnetic resonance imaging (MRI), intracranial magnetic resonance angiography, detection and management of severe carotid stenosis and atrial fibrillation are associated with improved outcomes for stroke patients (7, 23). Despite such advancements, some stroke patients continue to require rehabilitation post-acute care for deficits in the areas of spasticity (a condition in which certain muscles are contracted impacting normal movement, speech and gait) (24), upper and lower extremity dysfunction, shoulder and central pain, mobility and, dysphagia (difficulty in swallowing), vision, perception, and communication (6, 14).

Wade (1992) has defined rehabilitation as "a problem-solving and education process aimed at reducing the disability and handicap experienced by someone as a result of a disease" (25, 26). The WHO also provides a general definition of rehabilitation as "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environment" (27). Rehabilitation begins as soon as a patient becomes medically stable after the stroke event and when a patient's goals for rehabilitation and recovery can be identified (14). Rehabilitation takes places in a range of care settings including acute inpatient care, inpatient rehabilitation units, and outpatient and community-based settings (14). The length of the rehabilitation period is dependent on the individual's needs and the resources available within each care setting (14). A multi-disciplinary team that consists of physicians, physiotherapists, occupational therapists, speech-language therapists, nurses, and social workers works with stroke patients in helping them recover post-stroke deficits using a number of interventions (14, 28). These interventions are categorized into those that aim to reduce disability and those that aim to reduce the psychological and social consequences of stroke (29).

Reintegration is a gradual process as significant time is required to recover physical function and re-establish independence (30). Robust evidence based on systematic reviews of Randomized Controlled Trials (RCTs) has shown that standalone rehabilitation interventions are significantly beneficial to address disability, particularly motor impairments (31). High-intensity physiotherapy improves outcomes in gait and walking speed and interventions such as constraint-induced movement therapy improves outcomes

in arm function (31). In one multi-centered RCT, participants that received constraint-induced movement therapy showed greater improvements than the control group as they took significantly less time to complete given tasks based on a motor function test (32).

Other trials have explored the use of occupational therapy for improving Activities of Daily Living (ADLs) among stroke survivors. A 2017 Cochrane systematic review that assessed nine RCTs with 994 stroke participants, concluded that occupational therapy can improve ability in stroke survivors to perform ADLs and reduce the odds of deterioration in performing those abilities (33). However, no association between occupational therapy and mortality or the reduction of combined odds of death and dependency, death and deterioration or death and institutionalization was found (33). In addition, there was also no link found between occupational therapy and mood or distress (33). A meta-analysis of community occupational therapy in 2004 included eight single blinded RCTs that measured ADLs as their primary outcome. Results showed that stroke patients receiving community occupational therapy performed better on ADL scores (34). Findings also suggested that occupational therapy is likely to benefit the older population since they exhibit greater activity limitation than younger adults and have more potential to gain from rehabilitation (34). Similar results were found in a 2017 systematic review of community occupational therapy that targeted improving performance in ADLs (35).

Speech language therapy also has supporting evidence for helping stroke survivors with language impairments (aphasia). Based on existing literature, aphasia related impairments affect one-third of stroke survivors (36). A 2018 systematic review of RCTs found 27

studies including 1620 people with aphasia, which provided evidence of speech and language therapy benefits such as improvements in listening or reading as well as speaking or writing, in comparison with individuals with no access to therapy (37).

Between 27% and 64% of individuals experiencing a stroke develop dysphagia (difficulty in swallowing) (36, 38, 39). However, evidence for therapy targeting swallowing difficulties is mixed as a recent systematic review of RCTs found no link between swallowing therapy and functional outcomes (death or dependency, or death or disability), although swallowing therapy did seem to somewhat improve overall swallowing abilities (36).

While the information described above presents evidence for rehabilitation by single disciplines (e.g., occupational therapy, physiotherapy, etc.), evidence also exists for specialized stroke care in acute or inpatient units (i.e., specialized inpatient care using an organized multi-disciplinary team approach). A 2013 systematic review of RCTs concluded that individuals receiving specialized stroke care in acute inpatient units are more likely to survive, regain independence and return home, than those receiving regular care (i.e., less organized general acute inpatient care) (4).

Outpatient or community-based rehabilitation is an important part of the stroke rehabilitation system. Once a stroke patient is discharged from an acute inpatient care unit or an inpatient rehabilitation site, the immediate concerns on returning home are related to Activities of Daily Living (ADLs) that include personal skills such as dressing, washing,

feeding as well as extended skills including walking, leisure and other domestic skills (16). The long-term concerns consist of returning to normal living, for example, being able to return to work, being able to drive and being able to participate in social activities. In addition, the extra burden on families and caregivers as stroke patients transition to home could negatively affect the rehabilitation recovery (16). Despite improvements made in the acute phase, 33% to 43% of stroke survivors will need ongoing rehabilitation in the community due to residual deficits (13).

Services such as Early Supported Discharge (ESD) have aimed to reduce the length of stay of stroke patients in acute settings by discharging them early with rehabilitation support in the community. Evidence suggests that an ESD service can reduce length of stay by five hospital days for patients with a moderate degree of disability (40). A systematic review of RCTs studied outcomes in individuals receiving rehabilitation therapy in the community in comparison with conventional care (or no care) (41). Results found community-based rehabilitation to be effective in reduction in death or deterioration in ability to perform ADLs) (41). However, the most effective intervention, site setting (outpatient or home based) and appropriate levels of service delivery was unclear (41). A systematic review by Hillier et al. compared outcomes in stroke survivors that received rehabilitation at home with those that accessed outpatient centers, and found home based rehabilitation to be superior to outpatient-based rehabilitation in the early phases (less than 6 months) of re-integration in the community (42). The benefits seemed to be more equivalent at the 6-month post discharge mark (42). The study found insufficient data to make specific recommendations about timing and intensity for clinical pathways (42).

While the effectiveness of stroke rehabilitation in acute care and inpatient rehabilitation settings is well known, evidence for which community stroke rehabilitation models of care yield the most optimal results is not clear (43). Lack of clarity also exists on how best to organize and implement stroke rehabilitation services in the community for stroke survivors that are discharged from hospital or inpatient rehabilitation sites (15). There is limited knowledge in understanding the optimal levels of the length and intensity of the rehabilitation interventions in community for stroke survivors (15, 16).

Other studies have reported long-term unmet needs for rehabilitation of up to eight years after a stroke (11, 12). A Canadian qualitative study by Vincent and colleagues in 2007 found that partially met and unmet needs for rehabilitation persisted in the community post discharge among stroke survivors, who mostly received acute and inpatient rehabilitation (11). In addition, Hopman and Verner, who studied the quality of life during and after inpatient stroke rehabilitation among stroke survivors, found that improvements made in the inpatient stroke rehabilitation phase could be significantly reversed if not followed by adequate rehabilitation resources and services in the community (5).

Other unmet needs such as lack of adequate transitional care at acute and inpatient discharge as well as education and information needs have also been identified in the literature (5, 44, 45). Such studies also highlight the importance of understanding the stroke survivors 'needs and their experiences in order to better organize rehabilitation services. Section 2.5 provides in-depth information on patient experience.

2.3 Stroke Severity

Stroke severity has generally been grouped into three levels: Mild, Moderate, and Severe (46, 47). Each group is defined using scores from the standardized assessment measure called the Functional Independence Measure (FIM™) (46).

The FIM™ was developed to assess the degree of disability and burden of care (48). It uses 18 items in six areas of function: self-care (eating, grooming, bathing, dressing, toileting), sphincter control (bladder and bowel management), mobility (bed, chair, wheelchair, toilet, tub, shower), locomotion (walker or wheelchair, stairs), communication (comprehension, expression) and social cognition (social interaction, problem solving and memory) (48). The tasks are rated on a 7-point ordinal scale from total assistance to complete independence. The FIM™ has been tested for use in many populations including stroke, traumatic brain injury, spinal cord injury, multiple sclerosis and older adults undergoing inpatient rehabilitation (48). The FIM™ has been tested for its psychometric properties including reliability and validity (49). Its responsiveness has also been compared with the Barthel Index (BI), another measure of disability (described in more detail in Chapter 5). Unlike BI, FIM™ attempts to also assess cognition as approximately 10% of first time stroke survivors develop dementia (50) Results have shown that FIM™ is similar to BI in responsiveness however, the cognitive area of the FIM™ was less responsive than the BI, FIM™ physical and FIM™ total (51). A faster physical recovery but slower cognitive improvement has been observed as one of the explanations for the reduced responsiveness

in cognition (51). The use of FIM™ requires a license and cost is dependent on the type of use. In Ontario, it is mainly used in inpatient rehabilitation settings (9). In acute care, a 6-item instrument called AlphaFIM™ extrapolated from the FIM™ items, is used to assess disability and facilitate transfer of patients from acute care to inpatient rehabilitation (52).

Patients with mild strokes are those that have a FIM™ score > 80 at the initial stroke on-set. These patients generally have small deficits in functional independence; therefore, they can be managed well in the community unless there is a specific issue that needs to be addressed on an inpatient stroke unit (46). Patients with mild strokes generally recover well however, their ability to achieve measurable benefits from rehabilitation is limited due to the "ceiling" effect as FIM is not as sensitive in mild and moderate strokes as it is in severe strokes.(46, 53).

Patients with moderate strokes fall under the FIM™ score of between 40 and 80 at the early onset. Moderate strokes are generally associated with a clinically significant hemiplegia or hemiparesis - weakness or paralysis on one side of the body (46, 47). This patient group is generally the main focus of most inpatient stroke rehabilitation. More than 85% of people with moderate strokes are discharged to the community (46, 54, 55). Patients with moderate strokes demonstrate improvements in all areas although they continue to require rehabilitation in the community since they are often partially dependent in some areas at the time of discharge (46).

Patients with severe stroke are usually unconscious at stroke onset with severe unilateral or bilateral paresis (partial loss of voluntary movement) (46). Stroke patients may also be considered more severe if they have a serious medical co-morbidity that adds complexity to the overall stroke disability and participation in rehabilitation (46). Unless a patient is younger, those with severe strokes are less likely to recover their functional independence, irrespective of the treatment (46). They also have the longest stays on rehabilitation units and are less likely to be discharged into the community (54, 55). With strong family and community supports, patients with severe strokes can make significant gains and be discharged home, however they do not improve as consistently as patients with moderate strokes (46).

2.4 Stroke Care System in Canada

In Canada, stroke is a leading cause of disability and the third most common cause of death (56-58). Approximately, 62,000 Canadians experience a stroke attack each year, equivalent to one stroke every 10 minutes (6, 14). The mortality rates from cardiovascular disease and stroke have declined by more than 75 per cent over the last 60 years in Canada (6). Raised awareness, better stroke care and improvement in the management of risk factors, have led to such steady declines (59). The reduction in mortality rates implies better survival rates as there are more Canadians (approximately 315,000) living with a wide range of stroke-related disabilities (6). Also, stroke is an age-related disease and the Canadian population is ageing. As Canadians get older, they will be more likely to have stroke combined with other multiple chronic conditions such as hypertension, diabetes, coronary artery disease,

and cancer, and needing more complex care (6). At the same time, stroke incidence among the younger population is also increasing Canada-wide and internationally (6, 60-62), which places a disproportionately large economic impact on survivors as they recover and re-integrate back to normal living during their most productive years (60). Increasing numbers of older people diagnosed with stroke and other chronic conditions, as well as the alarming rise of stroke in the younger population, pose serious burden and risk to the Canadian health care system, services and resources (6). It has been estimated by the Public Health Agency of Canada (PHAC) that the Canadian economy suffers a loss of $3.6 billion a year in health care related services, lost wages and decreased productivity due to stroke (6, 14). For stroke survivors, the initial care is based on specialized acute hospital stroke care but the greatest impact on survivors 'health and well-being as well as the cost to society is from the long-term consequences faced after leaving a hospital (15, 16). As more Canadians survive stroke each year, they will need more services to support them in their recovery process, which challenges Canada's health care system's ability to keep up with the increased demand (6).

Each provincial and territorial jurisdiction has unique models of stroke care based on the customization of their resources and priorities (59). The following sections describe the Canadian stroke care system and the care journey of stroke survivors across different care settings: emergency department, acute inpatient care, inpatient rehabilitation, complex continuing care, and outpatient or community-based rehabilitation. This information is primarily from a study by the CIHI that followed approximately 60,000 Ontario stroke

patients for four years (2006 to 2010) across different care settings (56). While this information is restricted to Ontario due to data limitations, stroke patients and care providers from other provinces or the territories experience similar journeys and challenges (56).

Patients that present initial stroke symptoms begin their care journey on a number of different care pathways, as described in Figure 1. The most common pathways for stroke patients are: 1) Emergency Department (ED) only, 2) ED to acute inpatient care, 3) Acute inpatient care only, 4) ED to acute inpatient care to inpatient rehabilitation, and 5) ED to acute inpatient care to complex continuing care. The following sections describe each pathway in greater detail.

Figure 1 - Stroke Care System in Canada
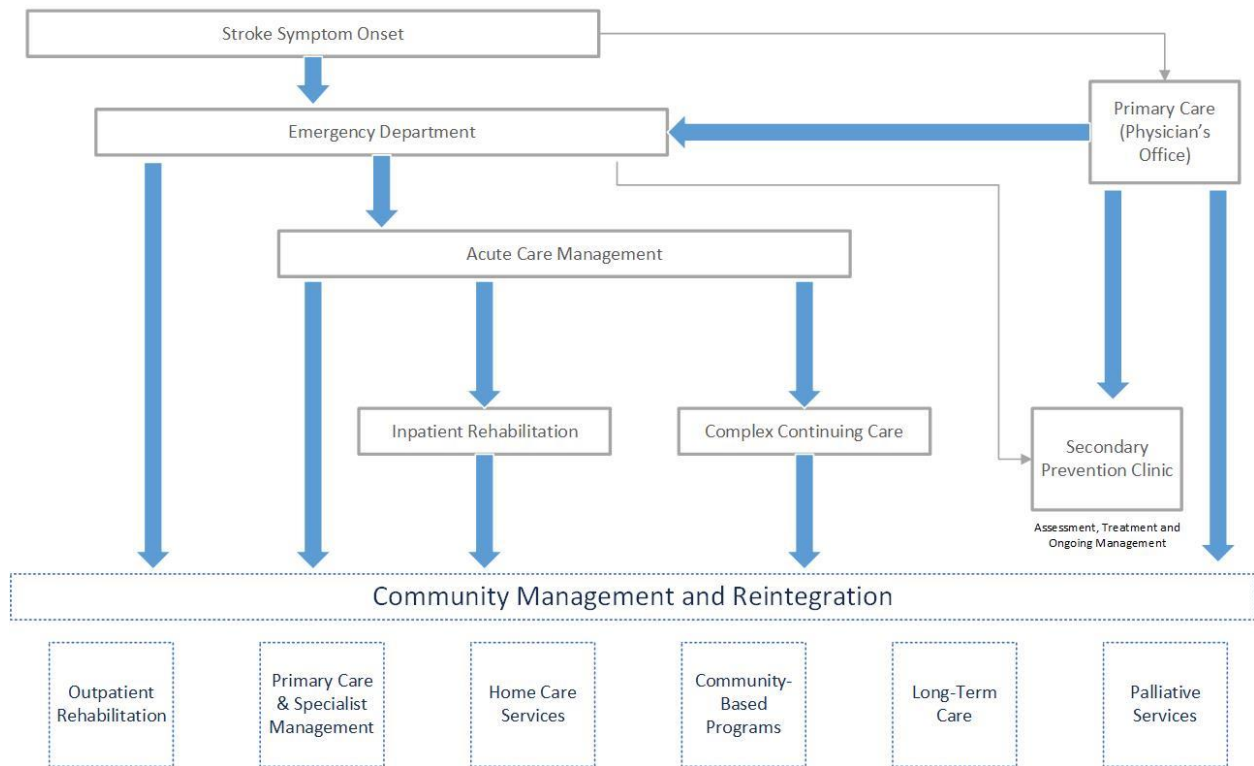
Figure 1 - Stroke Care System in Canada[1]

2.4.1 Emergency Department

Four out of five stroke care pathways include care provision in an ED as approximately 90% of patients with stroke episodes in a study by CIHI were first diagnosed with a stroke in an ED (56). However, only one-third of these patients arrived at the emergency department in an ambulance, despite the best practice recommendation to call 911 at first signs or symptoms of stroke (56). Access to rapid diagnosis and treatment is critical once the stroke signs or symptoms are present, since there is a short window to limit further damage to the brain (14). For example, patients with ischemic stroke (clogged artery) must arrive at a hospital within 3.5 hours of symptom onset (14, 56). However, according to the Canadian Stroke Network (CSN), a federal collaborative network of stakeholders to improve stroke care, only one-third of patients with stroke in Ontario and across Canada arrive to a hospital within 3.5 hours of the onset of their symptoms (56, 59).

Approximately 14% (8,753) of the 60,000 stroke patients in the CIHI study that presented initial stroke symptoms or were first medically diagnosed with stroke, required care only in an emergency department (56). Their care journey began and ended in an emergency department as they received no further care after their ED visit. Of these patients, 71% were discharged without any home care services, 21% were discharged to a long-term care setting or home with home care services, 6% died in an emergency department, and the remaining 2% ended their care for other reasons (e.g., leaving ED against medical advice, etc.) (56).

According to the Canadian stroke best practices, patients diagnosed with stroke in an emergency department should not be discharged without a clinical assessment and a plan for ongoing management (14, 56). However, very little information is available on follow up care including medication plans and potential referrals to the patient's primary care provider or a stroke outpatient clinic (56). An audit by the Ontario Stroke Registry, a data monitoring and research program, reported that stroke secondary prevention clinics received referrals for only 57% of stroke patients that were seen in an emergency department but were not admitted to inpatient care (56). While this audit noted an increased number in referrals over time, the report recommended that all patients who were diagnosed with stroke but not admitted to an acute inpatient care unit should be referred to a stroke secondary prevention clinic (56).
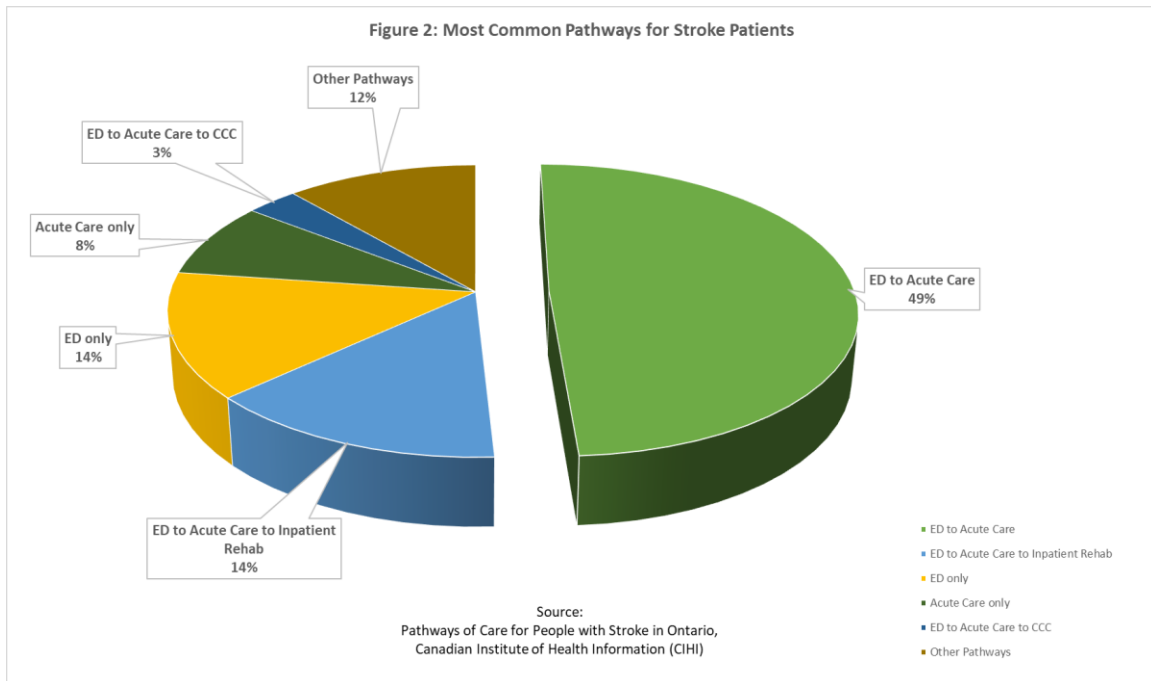
Figure 2: Most Common Pathways for Stroke Patients[2]

2.4.2 Acute Care

The most common pathway involved a stay in an acute inpatient care unit for patients that were initially diagnosed with stroke in an emergency department. Eighty-six percent (53, 614) of stroke survivors were admitted to an acute inpatient care unit at some point in their care journey (56). Approximately ten percent of patients admitted to acute care were not initially diagnosed with a stroke. It is unclear whether these patients had a stroke which was not diagnosed in the emergency department, or whether the stroke diagnosis was not documented in the patient's record (56). The lack of timely stroke diagnosis may indicate a negative influence on timely brain imaging as the CIHI found that patients admitted to

[2] Adapted with permission from Canadian Institute for Health Information. Source: Canadian Institute for Health Information (CIHI). Pathways of Care for People with Stroke in Ontario. July 2012. (See Appendix L for copyright permission letter)

acute inpatient care, that were without any stroke signs or symptoms in the emergency department, were less likely to have their brain imaging performed (56). Timely assessment through brain imaging is considered a best practice guideline as suspected stroke patients should be evaluated within one hour of emergency department arrival (59).

While in acute care, a comprehensive assessment of a patient's cognitive and functional status is also performed, with the goal of identifying impairments in the physical, functional, cognitive, and communication functions of a body (14). Such assessments assist clinicians with making decisions on rehabilitation treatment and discharge plans. In general, approximately 75% of stroke patients are left with impairment or disability, with two-thirds of patients having moderate to severe impairments (56, 63).

Timely and intensive access to rehabilitation improves outcomes post stroke (14), and delays in rehabilitative treatment can be detrimental to the recovery process (2, 64). The median Length of Stay (LoS) on acute care for stroke patients in Ontario was 11 and 20 days from stroke onset for patients transitioning to inpatient rehabilitation and complex continuing care settings respectively (56). It is also important to note that these measurements did not include the "Alternative Level of Care" or "ALC" days, a period when a patient who no longer requires acute services, occupies an acute care bed as they wait to be discharged to a more appropriate setting (3). Approximately 26% (14,266) of all stroke patients tracked by the CIHI, who were admitted to an acute care bed, had at least one ALC day whereas 18% (9,914) had 5 or more ALC days (56). The majority of these

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patients waited to be transitioned to complex continuing care (66%), an inpatient rehabilitation setting (45%), a long-term care setting (48%), and discharged home (10%) (56).

The combined waiting period of median LOS ranging between 11 and 20 days, in addition to ALC days, indicated severe implications for patient flow, higher costs of an avoidable stay in acute care, increased patient risk and poor patient outcomes (56). Studies have shown that early access to rehabilitation is associated with reduced risk of mortality and higher functional improvements (46, 65). Also, stroke patients with excessive bed rest have shown poorer outcomes (46, 66). This state of the stroke care system indicated that not only stroke patients were being put at risk by waiting excessively for a more appropriate destination, but lack of stroke best practices also cost the health care system avoidable financial burden in the shape of ALC days (56).

The Ontario Stroke Network (OSN), a provincial collaborative network for improving stroke care, recommended alignment of current stroke care with stroke best practices in 2012. The recommendations included: 1) timely transition of acute stroke patients to inpatient rehabilitation (i.e., Day 5 for Ischemic and Day 7 for Hemorrhagic from stroke onset) and 2) coordinated and effective discharge planning that involves stakeholders from hospital and community settings (9, 14).

The implementation of these best practices by the health service providers is expected to save significant annual savings in Ontario (9). Such savings could be applied elsewhere in

the stroke system, particularly in outpatient and community-based rehabilitation to support better community reintegration of stroke patients (9).

2.4.3 Inpatient Rehabilitation

The inpatient rehabilitation setting provides the most intensive and comprehensive stroke rehabilitation program (56, 67). The CIHI study found that one in four or about 29% of the stroke patients were transitioned from acute inpatient care to an inpatient rehabilitation setting (56). This proportion is higher than other reported figures as only 19% of patients were discharged from acute care to a rehabilitation facility according to a Canadian national audit (56). A report from the Canadian Stroke Network (CSN) suggests that as many as 40% of stroke patients could benefit from inpatient rehabilitation and that the current proportions of patients receiving inpatient rehabilitation could be higher (59).

Evidence suggests that inpatient rehabilitation is most beneficial for stroke patients with moderate to severe functional deficits (14, 46, 56, 68). Ontario has mandated the use of a Functional Independence Measure (FIM™), a standardized assessment tool to measure patients 'physical and cognitive functions, in all inpatient rehabilitation units (56).

As described earlier in section 2.3, stroke patients with a FIM score between 40 and 80 are considered to be the most appropriate candidates for inpatient rehabilitation (56, 68). Patients with FIM scores less than 40 (severely impaired) may not be able to tolerate intensive therapy whereas patients with a FIM score above 80 could be best managed at home if appropriate support or outpatient rehabilitation is available (56, 67).

Approximately half (47%) of stroke patients admitted to an inpatient rehabilitation setting had mild stroke-related impairment while close to one quarter (26%) of patients had a severe impairment, which indicates that relatively few severely disabled patients are being admitted to inpatient rehabilitation units (56).

In estimating the impact of moving to best stroke rehabilitation practices, OSN recommended implementing significant changes in inpatient rehabilitation settings. Such changes included providing rehabilitation needs in an outpatient or community-based rehabilitation program for mildly impaired patients that are currently admitted to inpatient rehabilitation units (9). In addition, patients admitted to CCC for "slow stream" rehabilitation are recommended to be served in an inpatient rehabilitation setting instead (9).

In terms of patient outcomes, 90% of patients are discharged with their goals met and 71% return home directly with a median length of stay of 31 days (14). Patients had significantly better scores at discharge (median FIM score of 107) than at the point of admission (median FIM score of 78) (56). The improvement in these scores clinically meant that a patient with a score of 107 would require 30 minutes of help each day from another person for daily activities whereas a patient with a score of 78 would require 90 minutes of help each day (56, 69). Nevertheless, the current length of stays could be further reduced by bringing efficiencies and increasing the therapy intensities in inpatient rehabilitation care (9). Specifically, it was recommended that inpatient rehabilitation units provide 3 hours of therapy per day, 7 days a week (9).

There are a number of potential benefits of aligning the current stroke system with stroke best practice guideline. Implementing best practices could result in earlier arrival of patients from acute care and also in fewer patients with mild strokes in inpatient rehabilitation, which would allow for more capacity to serve patients with greater acuity including those that are currently being served in a CCC setting. (9). The OSN estimated that it would require a net change of approximately 1000 rehabilitation bed days annually and 120 additional therapists/assistants on a full-time basis in Ontario to achieve best practice standards (9). The OSN's analysis also suggested that the investments will be completely offset by savings achieved in reducing the need for many CCC beds and also transitioning care for mildly disabled patients to outpatient or community-based rehabilitation programs (9).

2.4.4 Complex Continuing Care

The fifth most common pathway for stroke survivors encompasses the transition from acute care to a CCC bed. CCC provide care to chronically ill and medically complex patients under a specialized program over an extended period (56). These patients are generally more medically complex than those discharged to inpatient rehabilitation or home from acute care (56). The care required is usually not available at home or in long-term care facilities such as ventilation, special feeding systems, tracheotomy care and special pain management services. CCC beds are available in a free-standing facility or designated beds within acute care hospitals. CCC programs generally provide about five hours of rehabilitation a week for stroke patients (56, 70).

One in 11 or 9% of stroke patients were discharged from acute care to an inpatient bed in CCC (56). The functional status of a patient in CCC is measured by functional measures similar to the ones used in home care, including the Activities of Daily Living (ADL) Long Form and the Self-Performance Hierarchy scale (56, 59). Items on these scales are scored on a range from 0 to 6 with higher numbers representing greater need for assistance in daily activities (56). The CIHI study showed a significant improvement in physical functioning ability in stroke patients that were assessed at admission and every three months after; the median ADL score was 5 upon admission in comparison with the median ADL score of 4 on final assessment before discharge (56). However, 70% of CCC patients did not stay long enough to receive a second assessment and therefore were not included in the analysis (56). Note that functional measures used in home care are described further in section 5.1.4.

For those that were admitted to CCC, 33% were discharged home with or without home care rehabilitation, 35% were discharged to another care setting (e.g. Long-Term Care), 17% died while in care, and 8% transitioned to inpatient rehabilitation (56). The earlier section mentions the recommendation by OSN to potentially transition more severe stroke patients with potential for rehabilitation to inpatient rehabilitation (56, 67).

2.4.5 Outpatient or Community-based Rehabilitation
Of all the health care sectors, the home and community care sector has the least amount of data available on stroke survivors 'access and use of rehabilitation services (56). While the CIHI study was able to estimate the number of patients using emergency department, acute

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care, inpatient rehabilitation, and complex continuing care, limited information exists on the total number of referrals to outpatient clinics or community-based services (14, 56).

Despite the plentiful evidence of benefits of rehabilitation for stroke survivors as outlined in section 2.2, research suggests that Canada needs improvements in the home and community care sector for stroke rehabilitation and re-integration to normal living (7, 8). Evidence suggests that this sector has not been supported to provide adequate needs of the majority of stroke patients that require rehabilitation (9, 10). Data from rehabilitation facilities reflects insufficiencies of adequate community-based rehabilitation resources in nearly all regions of Ontario (9, 10).

The Community Care Access Centres (CCACs) that were responsible for providing access to home care in Ontario, were not providing home-based rehabilitation according to the Canadian best practices (9). Stroke patients receiving visits from CCACs for rehabilitation were receiving only an average of 3.9 visits in total (9, 71), which is not adequate according to the Canadian stroke best practice stroke guidelines. Canadian studies have estimated that approximately 13% of stroke survivors that were directly discharged home from acute care would require additional rehabilitation (72, 73). Best practice guidelines have also outlined that all patients discharged home from inpatient rehabilitation would require additional outpatient or community-based rehabilitation (9, 14).

According to the Canadian best practices, the following practices are recommended in the outpatient or home and community care sector (9, 14):

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- All patients discharged from inpatient rehabilitation should receive additional outpatient or community-based rehabilitation.

- Outpatient or community-based rehabilitation services should be provided within 48 hours of discharge from an acute hospital or within 72 hours of discharge from inpatient rehabilitation.

- Outpatient or community-based rehabilitation services should have the same service delivery elements as inpatient rehabilitation services, such as the following:

    - An interprofessional stroke rehabilitation team

    - A case coordination approach including regular team communications

    - Therapy should be provided for a minimum of 45 minutes per day per discipline (i.e., OT, PT, SLP, Social Work, etc.), 2 to 5 days per week, based on individual patient needs and goals, for at least 8 weeks

    - Patients and families should be involved in the stroke survivor's rehabilitation goals, management and transition plan.

Table 2.0 Comparison of current gaps in the Canadian Stroke Care System and recommended Canadian Stroke Best Practices		
Care Settings	Gaps in the Canadian Stroke Care System (9)	Canadian Stroke Best Practice Recommendations (9, 14)
Emergency Department	• Only one third of patients arrived in ED on ambulance • Only one third of patients arrived at a hospital within 3.5 hours of symptom onset • Only 57% of referrals were found for a stroke secondary prevention clinic from stroke patients seen in ED but were not admitted to stroke	• Call 9-11 at first stroke signs or symptoms. • Rapid diagnosis and treatment are critical: Patients with ischemic stroke must arrive to a hospital within 3.5 hours of symptom onset. • All patients that are diagnosed with stroke but not admitted to an acute care should be referred to a stroke secondary prevention clinic.
Acute Care Units	• The medial length of stays on acute care were 11 and 20 days for inpatient rehabilitation and complex continuing care	• All patients who require inpatient rehabilitation following stroke should be treated on a specialized stroke rehabilitation unit. • Timely transition to inpatient rehabilitation is recommended (i.e., Day 5 for ischemic and Day 7 for hemorrhagic strokes from onset).

Inpatient Rehabilitation and Complex Continuing Care	• Lack of specialized stroke rehabilitation units at inpatient rehabilitation settings • Only one quarter of patients receiving inpatient rehabilitation had a severe impairment • Only one half of patients receiving inpatient rehabilitation had a mild impairment • Current median length of stay is 31 days for inpatient rehabilitation	• All patients who require inpatient rehabilitation following stroke should be treated on a specialized stroke rehabilitation unit. • Mildly impaired patients should be provided with outpatient or community-based rehabilitation programs. • Some patients admitted to CCC for "slow stream" of rehabilitation are better served in an inpatient rehabilitation setting. • Length of stays could further be reduced by providing efficient and intense therapy (i.e., 3 hours x 7 days a week).

Outpatient or Community-based Rehabilitation	• Limited outpatient or community-based resources in all regions across Ontario
	• Stroke survivors have no access to a specialized community stroke rehabilitation program.
	• Stroke patients received only an average of 3.9 visits in total that were mostly for home safety assessment and not for rehabilitation.
	• Refer to Table 3.2 for further information on current gaps specific to the Waterloo Wellington LHIN.
		• All patients discharged from inpatient rehabilitation should receive additional outpatient or community-based rehabilitation.
		• Outpatient or community-based rehabilitation services should be provided within 48 hours of discharge from an acute hospital or within 72 hours of discharge from inpatient rehabilitation.
		• Outpatient or community-based rehabilitation services should have the same service delivery elements as inpatient rehabilitation services, such as following:
		   o An interprofessional stroke rehabilitation team
		   o A case coordination approach including regular team communications
		   o Therapy should be provided for a minimum of 45 minutes per day per discipline (i.e., OT, PT, SLP, Social Work, etc.), 2 to 5 days per week, based on

		individual patient needs and goals, for at least 8 weeks o Patients and families should be involved in the stroke survivor's rehabilitation goals, management and transition plan • Refer to 3.2 for further information on community-based rehabilitation best practice recommendations

2.4.6 Summary

Although progress has been made at national and provincial levels to achieve best possible stroke care in Canada, many gaps exist between best practices and current practices in stroke care (59). Efforts have been initiated since 2005 by the Canadian Stroke Strategy to mobilize the provinces to deliver best practice stroke care (59). Outpatient and community-based rehabilitation are an integral part of best-practice stroke care. In order to achieve outcomes from implementing best practices in acute care and in-patient rehabilitation sectors, timely rehabilitation in the community after hospital discharge is critical (9).

Stroke patients that received rehabilitation services (i.e., physiotherapy, occupational therapy, speech language pathology, social work) in the community received only a combined average of 3.9 home care visits total once they were discharged from the hospital into the community (9). Most of these visits were considered primarily for home evaluations and safety assessments and not for the purposes of rehabilitation (9). Therefore, it can be assumed that stroke patients received little to no rehabilitation services in the community after their hospital discharge. This highlights the gaps that exist in providing stroke rehabilitation care in the community. Implementing a best-practice stroke system would not only improve the quality of stroke care but also provide economic benefit to the health care system by freeing up acute bed days and shortening the length of acute care stays.

The gaps between current state and best practice standards highlight a significant opportunity to provide the best chance for community reintegration for stroke survivors.

Each province has a unique approach to improving quality of stroke care based on its resources and priorities (59). In Ontario, efforts to improve stroke care were part of the broader strategy to reduce the pressure of Emergency Departments and ALC days on Ontario's health care system (9). Significant savings and efficiencies can be achieved by implementing best practices (outlined in Table 2.0) in acute and inpatient rehabilitation sectors, which could potentially be re-invested on outpatient or community-based rehabilitation services (9).

In the transformed system where best practices are implemented, the burden of care provision would shift from acute care to outpatient or community-based resources with the focus on the appropriate patient in the appropriate care setting at the right time (9). For example, patients with milder rehabilitation needs would receive the majority of their rehabilitation care in the community, while the in-patient rehabilitation resources would be utilized by patients with severe rehabilitative deficits (9).

Implementing best practices through re-allocating existing resources would not only result in better patient outcomes but also improve patient experience. However, such a shift requires significant collaboration, commitment and buy-in from all stakeholders (emergency departments, acute care, inpatient rehabilitation units, complex continuing care, and community-based organizations). Chapter 3 provides more information on the improvements made in Ontario with regards to the stroke rehabilitation system.

2.5 Patient Experience

Patients with complex medical needs, including stroke survivors, require coordinated care from multiple care providers across the entire continuum of care settings (17, 74, 75). The unmet needs of stroke survivors as they try to rehabilitate their physical and social functions are described in Section 2.2. In addition, stroke survivors often have suboptimal experiences as they navigate through their rehabilitative care journey. Factors for such experience include poor transitional care (76), a lack of adequate information from care providers after a hospital discharge (77), a lack of organized care in the community after a hospital discharge (78), and lastly, a lack of information sharing among providers in the community (19).

Redesign of health systems is usually grounded on evidence-based practice and clinical pathways (79). However, efforts to engage with patients to understand their experience, with the goal of system re-design, are not made to the same extent (79). To develop a transformational stroke care system, listening to those living with stroke, particularly their needs, experiences and what matters to them is essential (12, 80-82). Many studies have shown an association between positive outcomes and improved patient experience through active participation of patients in clinical care (12, 79, 83, 84). Traditionally, health care systems have used patient satisfaction as a measure to evaluate which interventions are beneficial and acceptable to patients (85). However, patient satisfaction generally represents attitudes of patients towards their overall care or certain aspects of care (85).

Such information includes the gap between patient expectations and experiences but does not provide actionable information to improve care delivery (17, 85-87).

Recently, interest has emerged in understanding patient experience to identify opportunities for health system improvements and transformation (17). Patient experience is more comprehensive than patient satisfaction as it captures what took place during a care interaction and provides information that can be used to improve service delivery (17, 88, 89). Despite the increasingly importance of measuring patient experience, limited research exists on tools measuring patient experience in rehabilitation (17).

The following section describes the home & community care sector in the Canadian context; as well, it provides more information on how this sector is important for understanding the patient experience.

2.6 Home & Community Care in Canada

While home care services are not recognized as publicly funded services under the Canada Health Act of 1984, many provincial and territorial governments including Ontario have considered home care as a vital part of an overall effective health care system, and therefore administer publicly funded home and community care services (90, 91).

Ontario introduced its first publicly funded home care program in 1970 which included provision of nursing, rehabilitation therapy and personal support services (90). In 1997, the

government of Ontario established Community Care Access Centres (CCACs) that were responsible for arranging for delivery of home care services to people in their homes, providing information and referral to the public on community-related services, and coordinating placement and admission of residents to long-term care homes (90). The majority of the seniors who receive home care services in Ontario on an ongoing basis are female (60%), and about 40% are aged 75 or above (91).

Home care services begin with a referral from a range of sources including hospitals (at point of discharge), primary care providers, and clients themselves (91). Each referral is assigned to a care coordinator/case manager that meets with the client and/or a caregiver to conduct a clinical assessment using a standardized instrument (91). Based on the assessment, the care coordinator/case manager develops a service plan, authorizes services, and provides ongoing monitoring and evaluation (91). Services are typically provided by a personal support worker (assists with basic daily living needs) and a registered nurse that are usually employed by a community agency (91, 92). Other services may include professionals such as occupational therapists, physiotherapists, social workers, dietitians, pharmacists, nurse practitioners and physicians (91). Community support services include general housekeeping, meal preparation or delivery, transportation, and help with running errands (91).

Home and community care services have experienced a dramatic growth over the last two decades in Canada (93). Spending on this sector has increased four times more than spending on any other sector (93). Higher spending on this sector is attributed to the belief

that optimization of chronic disease management is best done in a community setting as opposed to in institutional care. This also benefits the health care system in terms of cost savings as care is redirected away from expensive hospital-based care to a community-based model (93-95). Home care has also been shown to be effective in delaying admission to long-term care facilities (95, 96), reducing future health services utilization (94, 96) and shortening acute care length of stays (97).

In the last decade, the number of patients discharged to home care services after a hospital stay has increased by 42% while the number of patients 75 year and older placed into long-term care homes has declined by approximately 25% (98). Other benefits are improved patient outcomes as home care services promote functional independence (99), reduce caregiver stress by providing respite care and emotional support (100) and lastly, enable clients in the community to stay in their own home for as long as possible (94). Benefits of rehabilitation in a home environment, including for stroke patients, have already been described in section 2.2.

The current structure of the home care sector in Ontario has resulted in a number of challenges. Complications have arisen from the fact that there are several different organizations providing care in the home (98). In addition, each organization has their own set of policies and procedures that results in variation in patient care and experience. There are approximately 160 contracted home care service providers that work with local health regions and close to 1,000 agencies providing community support services that include meal programs, transportation and homemaking services (98). Such a structure of home

and community care does not only result in complexity in coordinating care but also leads to duplication of resources. The following section provides more information on patient assessments.

2.6.1 Patient Assessments

Increasing demand of services and limited resources are often the challenges that exist in providing rehabilitation services (101, 102). To ensure the limited resources are allocated properly, it is important to have validated and reliable assessment instruments that can not only capture an accurate picture of a patient's status but also capture clinically relevant changes overtime (101). In addition, patients with medically complex conditions including stroke often require integrated rehabilitative care from multiple organizations in a community-based setting (75). While sharing information among health professionals is considered vital, understanding of how this information should be coordinated and used by different providers is limited (19, 103).

The two most commonly used instruments in stroke community rehabilitation are the BI and the RNLI (104, 105). In addition, the FIM is a commonly used assessment tool which is used in inpatient rehabilitation settings. All of these tools have well established psychometric properties including reliability, validity and responsiveness. In addition to these tools, the interRAI HC instrument has been designed to inform and guide comprehensive geriatric assessment and care planning in home care settings in many jurisdictions (102). In Ontario, the provincial government has mandated the use of the interRAI HC for care coordinators/case managers to perform an initial and an ongoing

assessment of home care clients. (Refer to 5.1 for more detail on the interRAI HC instrument). While this instrument has documented reliability and validity (102, 106, 107) and captures a standardized set of information including functional (e.g. ADLs), social (e.g. depression) and cognitive status of patients, its operational use has not been optimized in a way where information is shared and understood by other service provider agencies (19). Therefore, a lack of coordination among providers on patient assessments results in potential duplication of efforts and resources, increased burden on providers and poor experience for patients (19, 108). In addition, patient outcomes could potentially be at risk if relevant clinical issues are not recognized by all care providers (19). Both the BI and the interRAI HC's ADL scales (e.g. Long Form, Short Form) seem to measure similar aspects of a patient's functional status in terms of ADLs (104, 105, 109). However, only a limited number of studies have been found that compared the interRAI HC's ADL scales with other commonly used scales such as the BI (102) and the FIM(101). To my knowledge, there were no studies that specifically compared the psychometric properties such as responsiveness of interRAI HC's ADL scales with the BI in the stroke population in a community rehabilitation setting. The assessment of rehabilitation in older adults can be more challenging due to the large amount of patient variation resulting from a high burden of comorbid disease and the prevalence of cognitive impairment (101, 110). Therefore, it is important to understand how the standardized assessment instruments detect changes in patient outcomes if clinically relevant changes have really occurred – also known as responsiveness (101, 111, 112). Additional research on comparing responsiveness among the assessment tools used in the community for stroke rehabilitation

would provide guidance to promote information-sharing and reduce duplication in health

assessments. Note that the BI and RNLI are described in more detail in Chapter 5 under

section 5.3. (19, 108)

Chapter 3

Integrated Regional Strategy for Stroke Rehabilitation Care in the

Waterloo Wellington region of Ontario

3.1 Framework for Change

The earlier chapters have described the evidence for using best practice recommendations for stroke rehabilitative care. Also, gaps and opportunities in the current stroke care in Canada, particularly in Ontario, were summarized with regards to providing evidence-based care in settings such as acute care, inpatient rehabilitation care, and home and community care. Despite the availability of best practice evidence, getting research into practice is known as challenging and has been described in the literature as 'complex', 'messy', and a 'demanding task '(113). The following sections demonstrate the efforts made in the region of Waterloo Wellington by the local health system partners and stakeholders to develop and implement an integrated regional strategy for stroke rehabilitation care. To describe this implementation in a succinct and structured way, the information is presented using the PARIHS (Promoting Action on Research Implementation in Health Services) framework.

The PARIHS framework was developed in the United Kingdom by a team at the Royal College of Nursing that had significant implementation experience in research, practice development and quality improvement projects (113). According to this framework, successful research implementation is a function of the relationship among three elements:

evidence, context, and facilitation (113). Based on a retrospective analysis of studies

undertaken by the developers of this framework, it is suggested that in order for the

implementation of evidence to be successful, evidence needs to be scientifically robust,

match professional consensus, and carry the potential to improve patient experience (113).

For the second element, the context needs to be receptive to change with sympathetic

culture and strong leadership. The third element, facilitation, needs to have resources with

appropriate roles, skills, and knowledge to help individuals, teams, and organizations to

apply evidence into practice (113). The following sections describes the work undertaken

in Waterloo Wellington using the PARIHS framework and its elements:

3.1.1 Evidence

In addition to the evidence described in the earlier sections with regards to the gaps in the

Ontario stroke care system, results from the 2012 Ontario Stroke Network report card

highlighted that stroke survivors in the Waterloo Wellington region had limited access to

quality stroke care. This cohort also exhibited health outcomes that were below the

provincial benchmarks (114). The following table presents the comparison of key stroke

indicators in the WWLHIN and the provincial benchmarks.

Table 3.0 Comparison of Waterloo Wellington performance against provincial benchmarks[3]		
Best Practice	WWLHIN	Provincial Benchmarks
Stroke/TIA patients are treated on a stroke unit at any given time during their stay	43.9%	87.5%
The proportion of ALC days to total length of stay in acute care	36.9%	14%
Acute stroke (excluding TIA) patients discharged from acute care are admitted to inpatient rehabilitation	29.4%	42.3%
Patients with severe stroke are admitted to inpatient rehabilitation	27.4%	46.9%
Proportion of stroke/TIA patients discharged from acute care to LTC/CCC	13%	4.7%
Mortality	15.4%	14.3%

Results in Table 3.0 highlight that residents in Waterloo Wellington were not receiving care through a high-quality stroke care system (114). Fewer stroke patients were being admitted to inpatient rehabilitation from acute care than the provincial benchmark whereas stroke survivors were having more ALC days in acute care waiting for other destinations (e.g. LTC, CCC, home care). On the other side, significantly more patients were being discharged from acute care to LTC or CCC, indicating the lack of adequate community-based resources in the community (114).

In the feedback obtained during community engagement sessions during 2011-2012 by the WWLHIN in partnership with the local Stroke Recovery Associations, residents and

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[3] Source: Ontario Stroke Network Report Card 2012

stakeholders in the community did not have a positive experience in accessing current stroke rehabilitative care across the continuum of care (114).

Evidence on best practices, poor local performance and lack of positive experience became the drivers to initiate the improvement process in the Waterloo Wellington community. Further details on this process are described in the second element of the PARIHS framework, "Context".

Waterloo Wellington's Integrated Stroke Rehabilitative Care System
Elements of Promoting Action on Research Implementation in Health Systems (PARIHS) framework

Evidence → Context → Facilitation

Research

- Canadian Stroke Best Practice Recommendations
- Stroke Quality Based Procedures Clinical Handbook
- Ontario Stroke Network Report Card

Clinical Experience

- Impact analysis of moving to best practices - Ontario Stroke Network
- ALC Expert Panel
- Clinician's feedback

Patient Experience

- Stroke Survivor's experience
- Challenges accessing Rehabilitation services

Leadership

- Leadership passing motions to support integration
  - Waterloo Wellington LHIN's
  - Regional Acute Care Hospitals (Grand River Hospital and Guelph General Hospital)
  - Regional In-patient Rehabilitation Hospitals (Grand River Hospital – Freeport, St. Joseph's Health Centre, Cambridge Memorial Hospital)
  - Home & Community Care Sector (WWCCAC)

Culture

- Implementing Stroke Best Practices fits with strategic goals at each organization
- Allocated adequate resources (human, financial, equipment)

Evaluation

- Current Gap Analysis

Role/Purpose

- Regional Partnerships & Collaborations
  - Rehabilitative Care Council
  - Stroke Stream Steering Committee
  - WW District Stroke Council
  - Integration Task Force
  - Clinical Subcommittees
- Implementation Teams at each organization
  - E.g. WWCCAC's Stroke Implementation Team

Skills and Attributes

- Sustained Partnerships with stakeholders
- High Intensity
- Project Management

Figure 3.1 – PARIHS Framework – Waterloo Wellington's Integrated Stroke Rehabilitative Care System

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3.1.2 Context

Malone et al. (2004) argue that a strong context is required to ensure a favorable environment to action evidence into practice. Factors such as role clarity, decentralized decision making, and transformational leadership are some of the key ingredients that will result into higher chances of successful implementation (113). In light of the local evidence of poor outcomes and patient experience for stroke patients in the Waterloo Wellington health region, the leadership of the health region across the continuum of care acknowledged that transformational changes were required to implement an evidenced-based integrated model for stroke patients (115). As a first step of change, the leadership and the board of the WWLHIN passed a motion in which the WWLHIN would review hospital services and budgets as one system of acute care and reallocate resources to create a truly integrated and sustainable local health system (115). Subsequently, senior leadership of hospitals and their boards also passed motions that supported such integration activities (115). The vision was to develop a regional integrated program that will ensure a single standard of care and access to services regardless of where one resides. Similarly, the home and community care sector also committed to partnering with the acute care sector stakeholders to develop an evidence-based community stroke rehabilitation model that is integrated with the regional program (115).

3.1.3 Facilitation

Facilitation is the third element of the PARIHS framework, which suggests that the facilitator role, is fundamentally the one that supports clinicians to change their practice (113). A number of committees played the role of facilitation in implementing best

practices in the Waterloo Wellington community. To implement the vision of developing an integrated regional program for stroke services, acute care hospitals, in-patient rehabilitation hospitals and the local community partners, allocated resources (management and front-line staff) to create a number of committees and other collaborative planning groups. For example, the stroke stream steering committee played a role to direct and oversee the development and implementation of a stroke system of care in the WWLHIN across the continuum of care and was integrated within and across organizations (114). Based on the review of best practices, a pathway was developed for stroke patients from the emergency department to the community re-integration phase of stroke survivors (115). The WW Stroke Education committee was tasked specifically to ensure front-line health professionals (including home care healthcare professionals) were up to date on clinical best practices and the relevant required competencies in performing their clinical tasks. A number of education and orientation days were organized by the committee where staff from different care settings were invited (114).

This model of care was implemented across the continuum with the following goals (116):

- To provide a more comprehensive continuum of best practice stroke care for the stroke patient population.

- To ensure that stroke patients are assessed and triaged to the most appropriate level of care to meet their unique care needs.

- To ensure patients receive the Right Care in the Right Place at the Right Time to meet their recovery needs.

3.2 Acute Care and Inpatient Rehabilitation Model of Stroke Care

The regional stroke model of care introduced a number of changes in the acute care and inpatient rehabilitation settings including the implementation of best practices described in Table 2.1. Firstly, dedicated stroke care centres at specific acute care sites (Grand River Hospital and Guelph General Hospital) were established (116). Ambulatory services were coordinated with the local Emergency Medical Services (EMS) so patients that present initial stroke signs or symptoms in response to a 9-11 call would be routed to the designated stroke care centres instead of their nearest community hospital (116). Previously, stroke patients could have gone to any of the seven acute care hospitals in the Waterloo Wellington region. Such dispersion of patients did not allow for a critical mass of stroke patients for the provision of specialized stroke services (115). Having dedicated acute stroke care centres would allow for the implementation of stroke best practices more effectively (115).

Secondly, a "banding model" was introduced to assess and triage stroke patients more effectively based on the severity of their stroke and other factors (116). This model was designed to streamline early access and flow of patients to specialized stroke care for all levels of stroke severity. Patients diagnosed with stroke are admitted to an acute stroke unit where they are assessed by an interdisciplinary stroke team. Every patient undergoes a standardized assessment to have their functional status evaluated, which would then result in a seamless triage to a specialized stroke "band" of rehabilitation (116) . Alpha FIM, a

standardized assessment tool to assess patient's disability and functional status in an acute setting, is used to assist with determining a discharge disposition (116). Other factors that are considered for triaging patients to different bands include: significant cognitive impairments that prevent learning and participation in rehabilitation, significant psychosocial issues, significant behavioural issues putting the patient or others at risk, pre-stroke functional status and frailty, and lastly, unwillingness to participate in rehabilitation (116).

Each band has a unique staffing model with specific rehabilitation intensity and interventions geared towards addressing the needs of the patients within a specific stream (115). All treatment plans are based on the assessment phase (Band 1) reducing the need for further assessments in other bands (116). Figure 4 describes the triage process of the banding model (116). According to this model, patients with minor stroke symptoms that are functionally independent (Alpha FIM >100) are discharged home with linkages to outpatient rehabilitation or other community support programs such as day programs and secondary stroke prevention clinics (116). Patients with mild cognitive and communication deficits (Alpha FIM > 80) are placed in Band 2 as they remain in acute care with a targeted LOS for 7 days where they receive high intensity rehabilitation to optimize functional independence (116). Patients with moderate cognitive deficits and those with moderate to severe aphasia (Alpha FIM 40-80) are placed in Band 3, where they are transitioned to inpatient rehabilitation with goals of having optimized independence in functional mobility, basic ADLs and IADLs (116). Patients with severe functional decline (Alpha FIM <40) or older patients with Alpha FIM between 40-60 with low tolerance for

rehabilitation are placed on Band 4 for a longer duration (LOS 42-49 days) with the goals of maximizing functional recovery, managing ongoing medical needs, and assessing for special needs related to dysphagia management, behaviour, mood, cognition, and other conditions (116). Patients with stroke that are palliative, unable to participate in Band 4 or have significant pre-existing cognitive or medical co-morbidities that limit their participation in an ongoing stroke recovery care, or patients with catastrophic stroke with no functional goals are placed in Band 5 (116). Their focus of care is prevention and management of complications following stroke, and advanced care planning such as placement to a palliative or long-term care bed (116).

Some stroke patients on Band 2 and all patients on Band 3 and 4 are eventually linked to outpatient clinic (if accessible) or placed on a community rehabilitation pathway (described in the next section) through a coordinated discharge approach (116).

In addition to the banding model, the following changes were made in the in-patient rehabilitation setting to align with the recommended stroke best practices (114, 116):

- Provide inpatient rehabilitation in dedicated stroke rehabilitation units.

- Access to inpatient rehabilitation is streamlined so that patients are automatically transitioned to rehabilitation without any formal referral. Patients with ischemic stroke are transitioned on day 5 from stroke onset and patients with hemorrhagic stroke are transitioned on day 7.

- Implement 7 days a week care model for admission and discharges including evenings and weekends.

- Provide longer and intensive rehabilitation therapy (i.e., move to 3 hours per day 6-7 days a week model from the current average of 1 hour of therapy per day, 5 days a week).

- Create dedicated stroke teams of nursing, medical, and allied health professionals.

Waterloo Wellington Stroke Banding Model

Determine need for admission

Band 1
Assessment & Triage
LOS 2-5 days
Location: GRH and GGH Acute Hospitals

Standard Assessment and Tools

- Specialized Stroke Team
- Alpha FIM (Day 3)
- MOCA
- NIHSS
- Family Support
- Review pre-morbid functional status and living environment

Discharge Home
- Outpatient Rehab within 7 days
- Community supports (Day Programs, Secondary Stroke Prevention)

Band 2
Alpha FIM > 80
Short Stay Acute Rehab
- High intensity
- Short Duration
Location: GRH and GGH Acute Hospitals
Targeted LOS: 7 days

Band 3
Alpha FIM 40-80
Inpatient Rehab
- Moderate intensity
- Moderate duration
Location: Inpatient Rehab at GRH Freeport, St. Joseph's, Cambridge Memorial Rehab
Targeted LOS: 15-26 days

Band 4
Alpha FIM <40 or older patient (40-60)
Inpatient Rehab
- Low intensity
- Long Duration
Location: Inpatient Rehab at GRH Freeport, St. Joseph's, Cambridge Memorial Rehab
Targeted LOS: 42-49 days

Band 5
- Severe Strokes
- Little or no improvement
Location: Appropriate setting such as Long-Term Care or wait at home, Palliative or Complex Medical Bed

Outpatient Clinic?

No

Community Stroke Rehabilitation Model of Care

Figure 3.2 Waterloo Wellington Stroke Banding Model

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3.3 Community Rehabilitation Model of Stroke Care

Similarly, home and community sector also re-organized stroke rehabilitation services and adopted community stroke best practices in the Waterloo Wellington region. A community stroke rehabilitation program was developed and integrated with the broader local stroke care system (115). This program was implemented at the same time as the implementation of the integrated stroke care system in the acute care and inpatient-rehabilitation sector (115).

The model includes providing rehabilitation care according to the recommended intensity by the Ontario Stroke Network (OSN). This program is designed for patients that require therapy services in the community upon their discharge from hospitals and rehabilitation sites (Band 2, 3 and 4) (115). The rehabilitation therapy services include 2-3 visits per week for 12 weeks from Occupational Therapists (OT), Physiotherapists (PT), Speech Language Pathologists (SLP), Registered Dieticians (RD) and Social Workers (SW), resulting in up to 52 visits in total for a three months period (115).

The goal of the program was based on a home care model that ensures early, intensive rehabilitative care delivered by specialized stroke teams for patients that require in-home rehabilitative care after their transition from acute care or inpatient rehabilitation care (115). The purpose of this community program was to deliver best practice community stroke care services that would improve patient experience and patient outcomes (21). Patients getting discharged through Band 2, 3 and 4 would be placed on this community

stroke program if they were not able to access an outpatient rehabilitation program (115). The program has the following components:

1. **Supported discharge and transitional care**: A designated stroke Care Coordinator from the home & community care sector will work closely with the acute care and inpatient rehabilitation site staff to support transition to home and/or outpatient/community rehabilitation programs (115). These dedicated stroke care coordinators have expertise in community stroke rehabilitation best practices and discharge/transition planning (115).

2. **Discharge linking meeting with the community Occupational Therapist and hospital multi-disciplinary team:** The purpose of the discharge link meeting is to create a shared understanding of the patient's needs and treatment plan across the continuum of care (115) . The presence of a community therapist at the discharge link meeting facilitates smooth transition for stroke patients and creates an opportunity for the community therapist to understand patient assessments and the hospital treatment plan (115). This removes assessment duplication by the community team agreeing to continuation of the treatment plan developed in hospital. Community therapists are required to attend discharge meetings at any one of the five hospital sites (GRH, GGH, Freeport, CMH, and SJHC) regardless of the assigned geography (i.e., Waterloo Region provider may need to go to GGH etc.). The community therapist's role at the Discharge link meeting is as follows (115):

- Participate in discharge link meeting at hospital site

- Confirm patient's current goals and treatment, progress and functional status

- Establish patient's goals for the community and home

- In collaboration with the hospital stroke team and home and community care coordinator, determine which therapy disciplines required in the community

- In collaboration with the hospital stroke team and care coordinator, determine need for home safety assessment prior to patient discharge from hospital.

- In collaboration with the hospital stroke team and home and community care coordinator, brief community stroke team on patient status and goals in preparation for initiation of community rehabilitation.

3. **Stroke rehabilitation clinical pathway based on best practice guidelines:** Rehabilitation therapy is provided for a minimum of 45 minutes per day (up to 3 hours per day), 3-5 days per week, based on individual patient needs and goals (115). The following are key activities by each rehabilitation provider (115):

a. Occupational therapy intervention is focused on activities of daily living and community reintegration/re-engagement.

b. Physiotherapy intervention is focused on falls prevention, mobility and motor recovery, including individualized exercise program.

c. Speech Language Pathologists and Registered Dietitians provide assessment and intervention for stroke survivors with dysphagia.

d. Speech Language Pathologists teach supportive conversation techniques for stroke survivors with aphasia.

e. Social Workers provide interventions to optimize psychosocial functioning.

f. Inter-professional communication is facilitated by a case conference at week 3.

g. The following table provides a distribution of home visits per discipline over a period of 12 weeks as per stroke best practice guidelines.

Table 3.1 – Maximum service visits per discipline for community stroke pathway	
Discipline	Maximum # of visits over 12 weeks
OT	16
PT	10
RD	2
SLP	18
SW	6
Total	**52**

Table 3.1 Maximum service visits per discipline for community stroke pathway

h. The number of visits and duration of the pathway are determined based on the following recommendations from the Ontario Stroke Network (115):

    i. Among patients in need of community-based rehabilitation, 100% of patients will require PT and OT and 50% of patients will require SLP.

    ii. Intensity of therapy is 2-3 visits per discipline per week for 8-12 weeks.

    iii. RD visits should be conducted based on clinical needs as per the recommendations of the Ontario Stroke Network.

4. **First home visit within 48 hours of discharge:** There is no best practice guideline that defines the time from discharge to initial in-home treatment (115). However, patients who receive early intensive therapy have improved outcomes (115). The lead OT, who is the most responsible community clinician that attends the discharge meeting, makes the home visit for rehabilitation within 48 hours of discharge from hospital (115).

5. **Consolidated in-home care for all service disciplines:** Previously, patients received in-home care from multiple service provider agencies resulting in: lack of communication, lack of common goal setting, and multiple assessments by

different disciplines (i.e., OT, PT, SLP, RD, SW, PSW and nursing) (115). Consolidated community service provision means that care for all disciplines is provided by a single service provider agency in the community (115). Such consolidation promotes development of specialized skills in the team for the stroke re-integration process and facilitates inter-disciplinary communication, use of most appropriate resources, and common goal setting (115).

6. **Linkage with Primary Care:** Prior to this model, primary care providers (i.e., family physicians and nurse practitioners) were not connected with the home and community care sector as they did not receive any information on rehabilitation plans in the community for their patients (115). In this model, patients placed on the community stroke rehabilitation pathway would have their primary care practitioner informed about the initial pathway plan as well as any follow up plans (115).

The following table (Table 3.2) demonstrates key components of the stroke community rehabilitation model and highlights how these components differ from the pre-implementation state in the Waterloo Wellington region.

Table 3.2 – Waterloo Wellington Integrated Community Stroke Rehabilitation Model of Care			
Community Program Component	Pre-Implementation State	Canadian Stroke Best Practices (9, 14)	Intended Outcome
• Supported Discharge Planning: Transition is coordinated initially by designated Stroke Care coordinators with a focus on system navigation and transition to outpatient or community-based rehabilitation.	• Home care coordinators are assigned to cases based on geography not by patient population group.	• Early supported discharge services provided by a well-resourced, coordinated specialized interprofessional team are an acceptable alternative to more prolonged hospital stroke rehabilitation unit care and can reduce the length of hospital stay for selected patients.	• Improved Patient Experience
• A 'Discharge Link' meeting with community OT/Most Responsible Clinician, hospital rehabilitation team, Community Care Coordinator, and Stroke System Navigator.	• Patient's discharge plan is developed and shared in community, but therapists re-develop a care plan based on their own assessment.	• Information shared across transitions should be complete, up-to-date, accurate and appropriate to the transition settings and information needs of the receiving healthcare providers. • The patient should have an up-to-date care plan defining ongoing medical, rehabilitation, psychosocial, and functional needs. The care plan should be culturally appropriate and take into consideration the patient and family's preferences and goals. The care plan	• Improved Transitional Care • Continuity of Care into community • Improved Patient Experience

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		should be available to everyone involved in the patient's care across the continuum	
• First home visit within 48 hours of discharge by community therapist	• Average time between discharge and initial in-home assessment visit is 7 days.	• There is no best practice guideline that defines the time from discharge to initial in-home treatment. However, it is known that time is function in stroke rehabilitation and that patients who receive early intensive therapy have improved outcomes.	• Improved patient outcomes (clinical)
• Stroke rehabilitation clinical pathway: Up to 52 visits of comprehensive therapy by a multi-disciplinary team including OT, PT, SLP, Social Worker and a Dietitian.	• Rehabilitation therapy was based on needs and not by population group. Stroke survivors received therapy visits mainly for home and safety assessment by a therapist.	To work effectively, early supported discharge services must have elements similar to those of coordinated inpatient stroke teams including: 1. A case coordination approach. 2. An inter-professional team of specialists in stroke care and rehabilitation working in collaboration with community-based healthcare professionals. • Intensity includes 2-3 visits per week per discipline for up to 12 weeks	• Improved patient outcomes (clinical)

• Consolidated In-Home Care for all service disciplines	• Patients would receive care from multiple service provider agencies.	To work effectively, early supported discharge services must have elements similar to those of coordinated inpatient stroke teams including: 1. A case coordination approach. • An inter-professional team of specialists in stroke care and rehabilitation working in collaboration with community-based healthcare professionals.	• Improved patient experience

• Linkage with Primary Care	• Communication with primary care regarding a stroke patient's care and progress within the rehabilitative care system is fragmented and inconsistent.	Post–acute stroke patients should be followed up by a primary care provider to address stroke risk factors, ongoing rehabilitation needs, and to continue treatment of comorbidities and sequelae of stroke. This follow-up ideally should occur at least every six months and for at least three years following stroke.	• Improved patient experience

3.4 Summary

The gaps highlighted between current stroke care and best practice recommendations for stroke care presented a unique opportunity for health care organizations and planners to develop an integrated stroke care system across the continuum of care. Community rehabilitation is a critical component of the regional stroke model of care (16). The community program described above is designed to eliminate the barriers that were in place in the pre-implementation state to deliver streamlined coordinated, patient centered stroke care (115). The integrated model ensures that patients who survive a stroke attack are given the best opportunity to recover as they try to regain their physical, social and cognitive functions in the home (21, 115). The intended outcomes of this model are to improve patient outcomes and experiences as they navigate through the stroke care system (115). The evaluation of this model will provide evidence about whether this model is effective in achieving its intended outcomes. The rationale of the proposed research study is described in the following chapter.

Chapter 4

Research Questions and Study Rationale

The objective of this proposed study is to evaluate the effectiveness of the community-based stroke rehabilitation model of care in the Waterloo Wellington health region through measuring patient health outcomes and patient experience. This study is guided by the following research questions:

Primary Research Question 1: What are the functional and depression related outcomes of stroke survivors that received stroke rehabilitation through the community stroke rehabilitation model of care? Can any improvements observed in stroke survivors be attributed to Waterloo Wellington's Rehabilitation model of care?

Primary Research Question 2: What is the experience of stroke patients that received care through the community stroke rehabilitation model of care?

Secondary Research Question 3: How do the psychometric properties of responsiveness and construct validity of specific scales embedded in interRAI HC instrument compare with those of the BI and RNLI instruments?

There are a number of rationales for the proposed study. Significant investments in resources have been made to reorganize and integrate the stroke care system with the intention of improving patient outcomes and patient experience (20, 114). Such

reorganization and integration can be considered as complex interventions that not only show sensitivity to the local context but also "exhibit complexity in the causal chain linking the intervention with the outcome" (16, p294). Therefore, the results of this study will help understand the outcomes of implementing such a complex intervention.

This study also aims to fill a number of gaps in the current research literature on community-based stroke rehabilitation. As described in Chapter 2, the successful outcomes of organized stroke rehabilitation are well known in the acute care and inpatient rehabilitation care settings. Most community-based research in the literature has evaluated the outcomes of stand-alone therapies such as physiotherapy and occupational therapy (43). Less is known about specific models of stroke care for patients that continue to require rehabilitation in the community (43). Studies that have examined community based multidisciplinary rehabilitation interventions are limited and also lack the Canadian perspective as most studies are from the United Kingdom, Australia and the Scandinavian countries (43). This research study aims to evaluate patient outcomes and patient experience for a model of stroke care that not only provides evidence-based rehabilitation in the inpatient setting but continues to provide evidence-based rehabilitation in the community after a hospital discharge.

Furthermore, the process and structure of organizing community-based stroke rehabilitation as well as the length and intensity of rehabilitation interventions in the community continue to remain unclear (16). Elements in this community-based stroke

model include specific interventions that are aimed to improve patient experience. For example, the "discharge link meeting" between hospital and community providers aims to improve patient and caregiver experience at the point of transition from institutional care to home (115). Results from this study will provide a unique insight about the implementation and delivery process of the model with a specific length and intensity of rehabilitation (i.e., 45 min of rehabilitation, 2-3 times per week per discipline).

Additionally, a lack of coordination among providers on information gathering and sharing results in duplication of effort and resources, increased burden in assessments and frustration or poor experience for patients as they repeat their story multiple times (18, 19, 108). This study looks to examine the responsiveness and construct validity of the interRAI HC, BI and RNLI instruments that are used in the patient's home for patient assessments. Results from this analysis may identify opportunities to optimize limited resources.

Lastly, if the results are positive, the evidence gained from evaluating this pathway will not only help to sustain and improve this model of care but also help to expand this model to other regions across Canada and worldwide.

Chapter 5

Methods

Research methods used in this study vary for each research question. Therefore, we have organized the methods by each research question as following:

5.1 Research Question 1

What are the functional and depression related outcomes of stroke survivors who received stroke rehabilitation through the community stroke rehabilitation model of care? Can any improvements observed in stroke survivors be attributed to Waterloo Wellington's Rehabilitation model of care?

5.1.1 Study Design

An observational study design using multivariable propensity score risk adjustment to reduce treatment selection bias was used to evaluate functional and depression related outcomes.

In observational studies, inferences about the relationship between exposure variables of interest and outcomes can be affected by inadequately addressing the effect of confounding variables, including confounding by indication (117). Since clinical assessment is often used to determine a particular treatment, patient and facility-level characteristics can set a treatment pattern, which may influence outcomes. Confounding by indication and other forms of confounding can obscure the effect of treatment as the two groups will be non-comparable with regards to the distribution of the confounding factors. To minimize the

resulting bias, a propensity score method (covariate adjustment) was carried out to evaluate

the effects of the community stroke rehabilitation model of care, which is further described

under section 5.1.4.

5.1.2 Participants

The study consists of two types of participants: a treatment group and a control group.

1) Treatment group:

The participants in the treatment group of this study were stroke patients in the Waterloo

Wellington health region that received community rehabilitation through the new model of

care after their discharge from the local community hospitals or the local rehabilitation

hospitals during the period of April 2014 to April 2017. According to the banding model

described in Chapter 3, these participants were placed on Band 2 (acute care to home),

Band 3 or Band 4 (inpatient care to home). The population to which the results of the

participants will be generalized are community dwelling adults who survived a stroke event

and received evidence-based rehabilitation in the home.

2) Control group:

The participants in the control group were individuals residing outside of the Waterloo

Wellington LHIN region who had a stroke event during the same period and received only

the traditional home care based rehabilitation (or no rehabilitation)after their stroke-related

hospital discharge. The traditional home care services in many regions in Ontario did not

provide evidence-based community rehabilitation (i.e., rehabilitation intensity and

duration) during this period in Ontario, therefore it is reasonable to assume that they do not

receive the same treatment as compared to the ones in the treatment group (9) This was confirmed by contacting each of the Ontario's LHIN regions . Participants were excluded from some regions of Ontario such as Hamilton Niagara Haldimand Brant (HNHB) LHIN and South West LHIN where more intensive community stroke rehabilitation services were available than the traditional care.

5.1.3 Data Source

The data for the treatment group was retrieved from the Waterloo Wellington Local Health Integration Network (LHIN)'s home and community care database. The dataset includes demographic information as well as clinical information based on the interRAI HC instrument (refer to section 5.1.4 for more information on the interRAI HC) performed by regulated health professionals that function as "Care Coordinator" for patients in the home & community care sector (91, 114). The comprehensive assessments were conducted in the participant's home as part of routine operational practice at initial (within 14 days post hospital discharge) and follow up (3 months) stages of the rehabilitation program. This assessment data was extracted for secondary data analysis for this research study. Rehabilitation therapists from contracted home care agencies also collected an initial and follow up assessment of each stroke patient using the Barthel Index (BI) and Reintegration to Normal Living Index (RNLI) instruments (91).

The data for the control group were retrieved through the province wide interRAI HC repository at the CIHI, which collects data from all the local LHIN regions. The dataset

included demographic information (e.g., age, sex, marital status) as well as clinical information from the inter RAI HC instrument. While there were different sources for interRAI HC data used for the treatment and control groups, the methods of assessment and data collection were the same.

The following sections provide more information on the assessment instruments used in the home care settings including the interRAI HC, BI and RNLI.

5.1.4 Resident Assessment Instrument – Home Care

The Resident Assessment Instrument (RAI) Home Care (HC) is a standardized compression geriatric assessment tool that is used all across Ontario for care planning and service provision in the home and community care sector (118). This instrument was developed for use with adults in community-based settings by an organization called interRAI which is a collaborative network of researchers and practitioners in over 35 countries (119). The network strives to promote evidence-informed clinical practice and policy decision making through the collection and interpretation of high-quality data (119).

The instrument captures a patient's status in several areas including physical functioning, social functioning and cognition (120). Based on patient scores on these areas, information can be summarized through several RAI HC scales (120). Scales that measure functional outcomes of a patient are (120):

Activities of Daily Living (ADL) Long Form:

The ADL Long Form is a summative scale that consists of seven items that include bed mobility, transfers, locomotion, dressing (upper and lower body), eating, toilet use, and personal hygiene. This scale ranges from a score of 0 to 28 with higher scores indicating more impairment of self-sufficiency in ADL performance (121).

Activities of Daily Living (ADL) Short Form:

The ADL Short Form is a similar scale to the ADL Long Form and measures a client's ability to perform ADLs. It is based on four items that reflect early stage loss, specifically personal hygiene, toilet use, locomotion, and eating. This scale ranges from 0 to 16, with higher scores indicating more impairment in ADL performance (120).

Activities of Daily Living (ADL) Hierarchy Scale:

The ADL Hierarchy scale categorizes ADL items according to stages of loss (early, middle and late loss). The scale aims to reflect the disablement process rather than sum impairment of function. ADLs associated with early loss (e.g., personal hygiene) are given lower scores than ADLs associated with later stage loss (e.g., eating). This scale ranges from 0 to 6 with higher scores representing greater decline in ADL performance. The categories of this scale are as following: Independent (0), Supervision Required (1), Limited Impairment (2), Extensive Assistance Required I (3), Extensive Assistance Required II (4), Dependent (5), and Total Dependence (6) (120).

Instrumental Activities of Daily Living (IADL) Difficulty Scale

The IADL difficulty scale is a hierarchical index that sums up three IADLs: meal preparation, ordinary housework, and phone use. It is ranged from 0 to 6 with higher scores representing greater difficulty in performing these IADLs (120).

Instrumental Activities of Daily Living (IADL) Involvement Scale

The IADL involvement scale is based on seven self-performance IADL items: meal preparation, ordinary housework, phones use, managing finances, managing medications, shopping, and transportation. Each item is scored at 0 – independent, 1 – some help, 2 – full help, 3 – by others. Individual items are added to generate a scale that ranges from 0 to 21, with higher scores representing dependence on others in performing instrumental IADLs (120).

The following scales measure several other areas including depression, cognition, pain, patient needs and urgency and overall health stability (120):

Depression Rating Scale (DRS)

The DRS can be used as a clinical indicator of depression and is based on seven items that are embedded within the interRAI HC. The seven assessment items include negative statements; persistent anger, expressions of unrealistic fears; repetitive health complaints; repetitive anxious complaints; sad, pained, or worried facial expressions; and tearfulness (113). The scale ranges from 0 (no mood symptoms) to 14 (all mood symptoms present in last 3 days) (121). A score of three or more indicates the presence of symptoms of moderate

to severe depression (121). The DRS may be used as a potential screening instrument for depressive disorders. This scale has been validated against the Hamilton Depression Rating Scale and the Cornell Scale for Depression (120).

Cognitive Performance Scale (CPS)

The CPS scale is a hierarchical index that measures the cognitive status of a client based on assessment items such as short-term memory, cognitive skills for daily decision making, expressive communication and eating. This scale ranges from 0 (intact) to 6 (very severe impairment). A score of 3 or more reflects moderate to severe impairment. The CPS has been validated against the Mini-Mental State Examination (MMSE) (121).

Changes in Health End-Stage Disease and Signs and Symptoms of Medical Problems (CHESS)

The CHESS scale was developed to measure frailty and health instability. The scale identifies individuals at risk of serious decline and has been a predictor of death in the community and in long-term care settings. It also predicts hospitalization, pain, caregiver distress, and poor self-rated health. The scale ranges from 0 (not at all stable) to 5 (highly stable) (121).

Method for Assigning Priority Levels (MAPLe)

The MAPLe scale is a risk algorithm that assesses an individual's risk of adverse health outcomes. It assigns an individual to one of five risk categories: low, mild, moderate, high,

very high. Individuals in the lower risk categories are considered self-reliant, and have no major problems with function, cognition, behaviour, or their environment (121).

Pain Scale

The pain scale is based on two pain items of the interRAI HC: pain frequency and pain intensity. It creates a summary score that ranges from 0 (no pain) to 3 (daily severe pain). This scale has been validated against the Visual Analogue Scale (121).

The interRAI HC instrument has been tested extensively for its psychometric properties. A number of studies have reported this instrument to have acceptable levels of reliability (108, 121), responsiveness of physical status in geriatric populations (101) and convergent validity (122) including validity of its functional and cognitive outcome scales (102). Information on the BI and RNLI instruments is provided in section 5.2.

5.1.5 Outcome Measures

The outcome measures in relation to research question 1 are functional and depression related outcomes. The functional outcomes were measured using the interRAI HC's ADL Long Form, ADL Hierarchy Scale and the IADL difficulty scale.

Depression related outcomes were measured using the DRS. Other interRAI HC scales such as CHESS, CPS, MAPLe, and pain scale were used to compare baseline characteristics between the treatment and the control groups. (120)

5.1.6 Statistical Methods

Descriptive analyses were conducted to characterize and compare the baseline characteristics of both the treatment and the control groups. The comparison was performed using the chi-square tests to compare the distributions of demographic variables (i.e., age, sex, marital status) and clinical variables (pain, cognition, medical complexity) between the treatment and the control groups. Frequency tables were created to describe the rehabilitation intensity of each service (i.e., occupational therapy, physiotherapy, speech language therapy, social worker, and dietitian counselling). The therapy intensity levels were compared with the recommended best practice guidelines to assess the extent to which best practice guidelines were followed. The next steps were to conduct the analysis using the propensity score method which is described in the following section.

5.1.6.1 Propensity Score Method

As described earlier in section 5.1.1, a propensity score method was used to evaluate the effects of the community stroke rehabilitation model of care. Propensity score analysis is a method that can be used to analyze an observational (non-randomized) study so that "it mimics some of the particular characteristics of a randomized controlled trial" (117, p399).

The selection of a treatment is often influenced by subject characteristics which are also associated with outcome, therefore baseline characteristics of treated subjects (i.e., stroke patients receiving the recommended best practice intervention) may differ systematically from those of untreated subjects (i.e., stroke patients that were not on a stroke rehabilitation pathway) (117). Propensity score analysis allows researchers to account for systematic differences in baseline characteristics between treated and untreated subjects when estimating the effect of treatment on outcomes (117). Propensity score matching is used "to reduce or eliminate the effects of confounding when using observational data" (117, p400).

There are four main types of propensity score methods that can be used to estimate causal treatment effects using observational data (117). These four methods are: propensity score matching, stratification on the propensity score, inverse probability of treatment weighting (IPTW) using the propensity score, and lastly, covariate adjustment using the propensity score (117).

In this study, propensity score analysis was conducted using the covariate adjustment method. While consideration was given to other methods, including the propensity score matching method, covariate adjustment was chosen as the method for this study; propensity score matching was difficult as a sufficient number of matched controls could not be found in the available data.

In the propensity score adjusted regression method, the outcome variable is regressed on the estimated propensity score together with a treatment indicator (123, p1203).

The first step of this method is therefore to estimate the propensity scores by running a multivariate logistic regression analysis (124). According to Staffa et al. (2018), the calculated propensity score can be "conceptualized as the patient's probability of being treated as a function of measured baseline covariates" (124, p2). A logistic regression model was run in which treatment status, (i.e., stroke patients receiving rehabilitative care vs. stroke patients not receiving rehabilitative care =0) is regressed on the baseline characteristics and potential confounding variables.

It was important to select variables in the propensity score model that have the potential to affect the outcome (e.g., functional or depression related status) and treatment assignment. The potential confounding variables were selected based on the association of stroke outcomes and the utilization of in-home rehabilitation services (i.e. treatment assignment). For example, several studies have found an association of age and gender with stroke outcomes. Older women experience greater disability post stroke than men (125). Women also tend to have more stroke onset at a later age than men (126). An increased risk of stroke has also been observed among men and women with changes in marital status (married to unmarried) (127). Recent studies have observed an association between stroke and cognitive impairment (128, 129) and frailty (130). Similarly, many of the same variables have also been associated with utilization of in-home rehabilitation services. For

example, a study by Armstrong and colleagues reviewed geriatric patients that received in-home rehabilitation and identified distinct clusters based on variables of age, gender, living status and cognition (131).

In light of above and on the basis of contextual grounds, the potential confounding variables selected were: age, sex, living status, cognition, pain, health instability (CHESS), and patient needs and urgency levels (MAPLe). It is possible that we are missing other potential variables that affect treatment assignment from our selected variables. This is further described in the limitations section.

Finally, multiple regression models with the propensity score adjustment were run to evaluate the treatment effect. The following section provide more information on the methods for the regression models.

5.1.6.2 Regression models using propensity score adjustment

A number of regression models were run to predict functional outcomes. In the first regression model, our outcome variable was the follow up score for the ADL Long Form. Since this variable was a continuous variable, a multiple linear regression model was used in which the dependent variable was the 3 months follow up score for the ADL long form scale. The independent variables were the baseline score for the ADL long form scale, the propensity score variable, and the treatment assignment variable (treatment = 1, control = 0).

In the second regression model, the functional outcomes were predicted using the dependent variable of ADL hierarchy scores at 3 months. As mentioned in the section 5.1.4, the ADL hierarchy scale evaluates outcomes in a number of categories: Independent (0), Supervision Required (1), Limited Impairment (2), Extensive Assistance Required I (3), Extensive Assistance Required II (4), Dependent (5), and Total Dependence (6). Since this dependent variable has more than two outcomes, a multinomial regression model was used in which the dependent variable was the 3 months follow up score for the ADL hierarchy scale. Outcome categories in the dependent variable were grouped for further simplification (Independent, supervision required/limited impairment, and extensive assistance required/dependent). The independent variables were the baseline score for the ADL hierarchy scale, the propensity sore variable and the treatment assignment variable. (treatment = 1, control = 0).

In the third regression model, the functional outcomes were predicted using the dependent variable of IADL difficulty scores at 3 months. As mentioned previously in section 5.1.4, the IADL difficulty scale evaluates outcomes based on assessment of difficulty for the IADLs of meal preparation, ordinary housework, and phone use. While the scale ranges from a score of 0 to 6 (no difficulty to great difficulty), difficulty categories in the dependent variable were grouped for simplification (no difficulty/minor difficulty, moderate difficulty, severe difficulty). Since this dependent variable has more than two outcomes, a multinomial regression model was used. The independent variables were the baseline score for the ADL hierarchy scale, the propensity sore variable and the treatment assignment variable. (treatment = 1, control = 0).

To evaluate the depression related outcomes, a multivariate logistic regression model was used in which the dependent variable was the 3 months follow up score for the DRS. The independent variables were the baseline score for the DRS, the propensity score variable, and the treatment variable (treatment = 1, control = 0). Note that the dependent variable, the DRS follow up score, was converted into a categorical variable with two categories: 1) DRS < 3 (no signs of depression or symptoms of depression), and 2) DRS > 3 having strong symptoms or major depression).

Note that since the baseline confounding variables were already adjusted for in the initial propensity score regression model, there was no need to adjust them again in the outcome regression models.

5.1.7 Research Ethics

All the data collected through the various instruments are collected and stored as part of routine operational practice in the WWLHIN's home and community care database, which is called the Client Health and Related Information System (CHRIS). Hence, no patient consent is required prior to collecting assessment data. Data used by the research team for this study did not have any personal health information that would allow identification of individuals. This protocol has received ethics clearance from the University of Waterloo's Office of Research Ethics (ORE). See Appendix E for documentation of ethics clearance.

5.2 Research Question 2

What is the experience of stroke patients that received care through the community stroke rehabilitation model of care?

While instruments such as the interRAI HC, BI and RNLI were available to assess functional and depression related outcomes in patients, patient experience was an area that such instruments were unable to measure. While many generic patient experience instruments existed, an instrument was required that not only evaluated patient experience but also evaluated the specific aspects of service delivery for the Waterloo Wellington's community stroke rehabilitation model. Through this study, a Patient Experience Survey for Community based Rehabilitation (PESCR) was developed and administered to measure patient experience.

5.2.1 Instrument Design

The Program Logic Model (PLM) was used as a framework to determine the broad domains and concepts that are relevant to the stroke service delivery model and should be assessed to capture patient experience. PLMs have been found to be quite useful by evaluators for over the last two decades (132). It presents a plausible and sensible model of how the program should work under certain conditions to address identified issues (132). The benefit of using this framework is that it builds a common understanding of the program and how each component of the model is linked to each other.

A PLM is comprised of four components: inputs, activities, outputs, and outcomes (132). Inputs are resources or infrastructure that are used as the foundation of the program. Activities include the specific tasks that are being performed by the staff to direct the course of change (132). They include any work or actions that are necessary to produce program outputs. Outputs are services that are provided to the program's direct customer (i.e., patients) (133). Outcomes are known as changes or benefits that result from the activities (133).

All the elements of the community stroke model are part of the inputs. For example, having a discharge link meeting and a consolidated service provider in addition to having the first home visit within 48 hours are all components that are part of the "Input". The specific work that is done during each of such components were the "Activities". As a result of such inputs and activities, there were immediate outputs such as number of people served and number of patients that had a home visit within 48 hours. These outputs were then expected to transform into "outcomes" which means improved functional status, or ability to return to normal living. The model displayed in Appendix F outlines the inputs, outputs and outcomes of the community stroke model. The inputs and activities have been merged together for simplicity.

Once the key concepts and domains were identified, instrument items were devised for each outcome (e.g., functional independence, improved transitional care, etc.). A research

report by the Geriatric Health System (GHS) research group at the University of Waterloo was used as a basis for further consideration on potential domains or scale items (134) . This report provided a systematic analysis of peer-reviewed literature on patient experience an patient experience measures (134).

To further ensure that the instrument captures all the items required to fully evaluate the community model from the patient's perspective, consultations were held regularly through the WWLHIN with health care experts and decision makers in home care service planning (n= 6). The experts included health care professionals at the WWLHIN and front-line members from the community stroke rehabilitation team. In addition, regular consultations were also held with stroke survivors (n=4) in the region of Waterloo through the Kitchener Waterloo (KW) stroke recovery chapter.

These groups were consulted to judge whether 1) relevant domains or items that would be relevant for each of the outcomes of the program logic model were included 2) items were comprehensive to capture patient experience across various health care sectors and 3) items on the instrument were worded clearly and appropriately. Face validity and content validity are described in the next section.

Additionally, consultations were also held with another research group associated with University of Waterloo and Wilfrid Laurier University that developed a patient experience measure called WatLX for ambulatory rehabilitation care settings. This instrument has

been tested for initial feasibility and shows promising psychometric properties, including high scores for internal consistency and reliability (87) Items from the WatLX that were related to patient experience and were relevant for the evaluation of the community stroke rehabilitation were included. The development of these question items and their content and face validity are described in a peer-reviewed published paper (17)

5.2.2 Face and Content Validity

Face validity is the degree to which an instrument appears to measure the variable that it is supposed to measure (135). It ensures that the items of each domain are "sensible, appropriate, and relevant to the people who use the measure on a day-to-day basis (135, p1894). As mentioned in the previous section, after the initial draft of the instrument, consultations were held with key stakeholders to ensure the questions in the instrument were worded appropriately and the instrument was clear and relevant to users.

Consultation also took place to test the content validity, which is defined as "the extent to which the set of items comprehensively covers the different components of health to be measured" (135, p1893). The tool that was used to test content validity was similar to the one that has been suggested by Streiner and Norman (136). Table 5.1 demonstrates how content validity can be checked. Each row represents a different item on the scale, and each column a different content area which was devised from the PLM. Every item is examined in turn, and a mark placed in the appropriate columns. There is no score or number that is generated at the end of this exercise [which could have been used for a content validity

ratio (136)], but the following chart provides helpful information in terms of content

validity. Refer to Appendix D for the final patient experience instrument.

Table 5.0 Content Validity for Patient Experience instrument					
Questions	Content Area				
	Overall Patient Experience	Transitional Care	Timely Access to Care	Integrated Care	Returning to Normal Activities
1-4		X			
5-7			X		
8-10				X	
13-16					X
20-24	X				

5.2.2 Methods

The participants involved in this study were the stroke survivors who participated in the community stroke rehabilitation pathway. The patient experience survey was administered after the completion of the rehabilitation pathway at the 3 months follow up stage. The consent letter (see Appendix B) was mailed out to the participants ahead of the 3 months follow up post-assessment visit by a care coordinator. At each follow up home visit, care coordinators explained the purpose of the research study and assured the participant of confidentiality and anonymity. Once an informed verbal consent was obtained, the survey was handed out to the participant for completion. Participation was based on the stroke survivor's ability to complete the survey based on the care coordinator's clinical assessment of health status (i.e., cognitive impairment). The participant's caregiver may have also been asked to provide consent and complete the survey if a patient was unable to participate. Upon completion, the survey was sealed in an envelope by the patient or their caregiver

and returned to the care coordinator who would place the envelope in a drop box located in the home and community care staff office building. Participants also had the option of mailing out the sealed survey directly to the researcher using a pre-paid envelope.

There were no known or anticipated risks to the participants as a result from the study. All participants were assured of patient confidentiality and anonymity. Participants of the survey had the chance to skip any question by leaving it blank and withdrawing from the study at any time by not returning the survey.

Participants that had already completed the community rehabilitation in the past (up to 6 months post-completion) but were unable to share their experience at the 3 months follow up visit, were provided with an opportunity to participate by telephone. Initial contact was be made by an administrative staff person using the phone script in Appendix C. The phone script stated that the administrative staff person was calling from the home and community care team on behalf of the researchers at the University of Waterloo. Informed verbal consent was obtained over the phone by explaining the purpose of the call and the rationale of the study. All participants were assured of complete confidentiality and anonymity. The time commitment required to administer the survey was approximately 20 minutes.

The completed survey data were entered in a spreadsheet that was placed on a secured network. Any patient identifiers (name, etc.) were removed for data confidentiality. The

data from the patient experience questionnaire were extracted and analyzed using Microsoft Excel and SPSS.

The construct validity of the patient experience instrument was measured by assessing the correlation between the global question (question 1.11 in table 7.9) and the overall score of patient experience questions. The correlation was assessed using the Pearson correlation coefficient.

The reliability of the patient experience instrument was measured by evaluating its internal consistency using the Cronbach's alpha coefficient, which measures the extent to which all items are consistent with each other (137). While other methods of measuring reliability (e.g. test-retest reliability) are considered to have more strength (138), the method of measuring reliability through internal consistency was chosen in this study as it only requires single administration of the instrument (138), a method that was deemed more feasible for this complex population by the research team.

The open-ended responses were assessed using the method of content analysis. A directed content analysis approach was used where pre-determined categories of "program's strengths" and "opportunities for improvement" were used to review open-ended responses. All open-ended responses were reviewed and passages that fit the pre-determined categories were highlighted. Sub-categories within each main category were identified based on the occurrence of a phenomenon. The findings from the content

analysis were summarized in a table format to provide a brief description of the sub-category and the percentage of the occurrence of all phenomenas.

5.2.3 Research Ethics

The ethical considerations that are pertinent to the evaluation of the stroke community model include patient privacy, consent and data confidentiality which have been outlined already in the earlier section. The protocol for administering the patient experience survey was cleared by the Office of Research Ethics (ORE) at the University of Waterloo. Ethics clearance can be found in Appendix E.

5.3 Research Question 3

How do the psychometric properties of responsiveness and construct validity of specific scales embedded in interRAI HC instrument compare with those of the BI and RNLI instruments?

5.3.1 Participants

Data were collected on participants that received the stroke rehabilitation program between April 2014 and April 2017. While the WWLHIN's Care Coordinators assessed patients using the interRAI HC instrument, rehabilitation therapists from the contracted service provider home care agency collected patient data using the BI and RNLI instruments.

These assessments were performed around the same time as the interRAI HC assessment (initial and 3-month follow up).

5.3.2 Barthel Index

The Barthel Index (BI) is an instrument that measures activities of daily living, particularly self-care and mobility (139). Since its inception in 1955, it has become one of the most commonly used tools to measure the efficacy of stroke rehabilitation (104). The BI instrument evaluates ten areas of activities that consist of feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers (bed to chair and back), mobility and stairs (42). The instrument's items have three-point scales with a total maximum score of 100 with more weight given to mobility and transfers (42). Lower scores indicate increased disability while higher scores indicate improvement in functional independence (104).

Several studies of its psychometric properties have supported the use of the BI as they found it to be valid and reliable (139-141). However, limitations exists as the instrument is relatively insensitive to change and is associated with a ceiling effect as it does not have any mechanism to reflect further improvements once a patient reaches the maximum score of 100 (41). Despite its limitations, BI is a commonly used tool for assessment in a community-based setting for stroke patients. A systematic review by Hillier et al. (2010) found that a majority (10 out of 15) of the randomized controlled trials reviewed used the BI as a measure of the overall level of activity or functioning (42).

Several authors have proposed modifications to the original BI instrument including re-ordering scale items (104, 140), changing or expanding definitions (142), changing scoring system (143) and adding/removing items (144). However, there is no consensus on the optimal version and not one particular version seems to be superior than others (104). In light of a lack of consensus, Quinn et al. (2011) argues that it is reasonable to use the original 10-point scale in future studies including any stroke randomized controlled trials (104). In the Waterloo Wellington's stroke community rehabilitation model, community occupational therapists also administer the original BI 10-point scale to measure initial and follow up functional status of stroke participants.

5.3.3 Reintegration to Normal Living Index

The Reintegration to Normal Living Index (RNLI) is an instrument that is used as an indicator of quality of life in various populations, including people with stroke (145). It is among the top ten frequently used instruments for assessment of outcomes in the stroke population (105). It specifically measures the degree to which individuals who have experienced traumatic or neurological conditions achieve reintegration into normal social activities such as recreation, movement in the community, and interaction in family or other relationships (105, 146). The instrument has 11 items and concepts are based on mobility, self-care, daily activity, recreational activity, and family roles (105, 145). Each item is rated on a 10-point scale with the lowest score (score of 1) indicating lack of reintegration and the highest score (score of 10) indicating complete reintegration (147).

A number of studies have tested the instrument for its psychometric properties. The RNLI has been found to demonstrate acceptable levels of content validity (148, 149) and face validity (150). Studies examining construct validity by comparing the RNLI with other instruments including the Barthel Index and the Hospital Anxiety Depression Scale suggested poor to strong construct validity, based on correlation coefficients ranging from 0.25 to 0.77 (105, 109). Various studies have been conducted to test the RNLI's reliability.

A recent systematic review of the RNLI's psychometric properties found ten studies that measured reliability through internal consistency, and all reported acceptable levels of internal consistency (Cronbach Alpha coefficients from 0.73 to 0.97) (105). Studies have also been conducted to investigate test-retest reliability and reported acceptable levels (Intraclass Coefficient (ICC) 0.71 to 0.87) (105, 149, 151, 152).

5.3.4 Statistical Methods

Responsiveness statistics were used to compare the inter RAI HC's ADL Long Form and DRS with the BI and RNLI respectively, in terms of their ability to detect clinically relevant changes in stroke patients. The interRAI HC's ADL Long Form scale was selected for comparison with the BI because both scales intend to measure functional status or motor function of a patient (104, 153). Although the interRAI HC instrument has a number of ADL scales, the ADL Long Form scale is chosen as it captures more functional assessment items than other ADL scales in the interRAI HC and is considered to be more sensitive to clinical changes than the other ADL scales (120).

For the comparison of the RNLI, the DRS scale was selected from the interRAI HC's set of scales. While both scales appear to measure different aspects of a subject's characteristics (i.e., the RNLI is a generic instrument that attempts to measure community reintegration and social participation, whereas the DRS attempts to measure depression), a number of studies have shown an association between depression and community reintegration (154). Higher levels of depression have been linked with lower levels of community reintegration in stroke survivors (149, 154, 155). Individuals who were able to have stronger community reintegration also have been found to have better outcomes in anxiety, depression, daily activity and quality of life (155). Therefore, it is possible that some level of association exists between the RNLI and depression and hence, the interRAI HC's DRS was chosen for comparison with the RNLI. (105, 109)

Internal responsiveness is defined as the ability of an instrument to detect changes in patient's health status over time if real clinically relevant and meaningful changes have indeed taken place (101, 111, 112). The two frequently used responsiveness statistics that were used in this study were the Standardized Response Mean (SRM) and Effect Size (ES).

The SRM is a ratio of observed change to the standard deviation of the change scores (111). The observed mean difference in scores were divided by the Standard Deviation (SD) of the differences in scores to calculate the SRM (111). The values of 0.20, 0.50 and 0.80 in SRM were considered small, moderate and large values of responsiveness respectively (156).

The ES can be defined as the magnitude of the difference between two intervention groups (157). To measure the ES statistic, the numerators (i.e., observed mean difference in scores) remained the same, however, the denominator was measured by the SD of the baseline scores (111). Therefore, ES is sensitive to the level of variability between the patients at baseline. Similar to SRM, ES values also reflect the magnitude of change. Values of 0.2, 0.5 and 0.8 were considered small, moderate and large values of responsiveness respectively (156).

Additional properties of each scale such as mean levels and proportion of scores at floor (floor effect) were also measured.

Construct validity of a questionnaire is defined as the extent to which a questionnaire measures what it intends to measure (158). In other words, does the questionnaire test what it claims to test? For this study, construct validity of the ADL Long Form and the DRS was verified by comparing these tests with other tests (BI and RNLI) that measure similar traits of a subject's characteristics. The level of agreement between the ADL Long Form and the BI was measured using the Pearson correlation coefficient. Similar comparison was performed to test the level of agreement between the DRS and the RNLI scales.

5.3.5 Research Ethics

Refer to Section 5.1.3 on research ethics. The same ethics process and approval applies to this methodology as well.

Chapter 6

Knowledge Translation & Dissemination Plan

It is expected that the results of this study would make important contributions to the stroke care body of knowledge and the current literature on stroke care. The study results show whether the recently developed stroke model of care has resulted in better outcomes and improved experience for stroke survivors in the Waterloo Wellington region of Ontario. Other study rationales and the importance of this study have been described in Chapter 4. Results of this study may have significant implications and it is hoped that the knowledge from this study will translate into action in practice and service delivery. For example, information from the patient experience survey has provided insight on what service delivery processes of the stroke rehabilitation pathway contribute towards improving experience than others and hence, identifying further areas of improvement and opportunities for the current model.

Results of this study will be disseminated through a number of methods. Firstly, results will be organized in a number of thesis sections with the aim of publishing each section in a peer-reviewed journal. The first paper will be a descriptive paper about integrated care and how these services were planned, implemented and evaluated. The second paper will comprise outcome results using the interRAI HC and other instruments including results from the statistical methodology of propensity score matching analysis. The third paper will compare the responsiveness of interRAI HC and other instruments (i.e., BI and RNLI).

Lastly, a paper about development and administration of a patient experience instrument, and the results obtained with this instrument, will also be written for publication.

In addition to disseminating results through peer-reviewed journals, results of this study will also be shared at the Canadian Stroke Congress – a national conference about stroke care, and also other conferences (e.g. Canadian Association on Gerontology and Home Care Summit). It is also expected that stakeholders from provincial and regional health regions would also be interested in the results of this study. Specific results from the analysis of interRAI HC, BI and RNLI instruments would also be shared at conferences such as Canadian interRAI conference which represents researchers, policy makers and clinicians using the interRAI system of instruments in community and home care, residential/long-term care, acute care, assisted living, mental health and palliative care (119).

Chapter 7 Results

7.1. Participant Characteristics

Five hundred and ninety-three (593) participants matched the inclusion criteria described in section 5.1.2. Of these, 479 participants were initially found in the treatment group out of which 75 (15.5%) participants were lost to follow up, hence, the final count for participants analyzed in the treatment group was 404. One hundred and eighty-nine (189) cases were found in the control group who did not receive any rehabilitation (or received traditional care) in Ontario after their stroke related hospital discharge.

In comparing the baseline demographic and clinical characteristics, the mean age of the treatment group was statistically lower than the mean age of the control group (76.9 ±9.5 vs. 82.1 ±13.0, $p < 0.001$). In comparison with the treatment group, fewer participants were found in the control group that were aged 60 and under (9.9% vs. 2.6%, $p < 0.001$). Overall, there were more females present in the entire sample (56.3 vs 43.7%). However, the sex difference was much higher in the control group (67.2% females vs 32.8% males). In terms of living status, fewer participants in the treatment group were living alone or not married (54.7% vs. 66.1%, $p < 0.01$). The average wait time for assessment in the community post-hospital discharge was 9 days (SD 12.7) in the treatment group whereas the average wait time for assessment was 21.2 days (SD 10.7) in the control group.

Participants were also assessed for clinical characteristics such as medical stability, cognition, care urgency and pain levels. Based on the CHESS scale for medical stability, more participants in the control group were categorized as moderate to highly unstable (28.6% vs 20.5%, $p < 0.10$). There were also more patients in the treatment group that were intact for cognition (16.6% vs. 13.8%, $p < 0.001$) whereas the control group had more participants that were severely impaired for cognition (9.5% vs. 0.2%, $p < 0.001$). Based on the MAPLe scale, proportion of participants with higher care urgency levels in the treatment group was less than the proportion of participants with higher urgency care levels in the control group (53.5% vs 59.3%, $p > 0.05$). However, the difference between the two proportions was not statistically significant.

In terms of pain levels, a higher proportion of participants in the treatment group reported having no pain than did the participants in the control group (46.3% vs 40.7%, $p > 0.05$). The proportions of participants reporting daily severe pain (score of 3 and above) in the treatment and control group were 6.4% and 6.9% respectively. The difference in proportions was not however, statistically significant.

Refer to table 7.1 for more information on baseline characteristics for the treatment and control group.

Table 7.1. Baseline Characteristics for Treatment and Control Group

Baseline Covariates	Community Rehabilitation Group (n=404)		No Community Rehabilitation Group (n= 189)		Total Cohort (n= 593)		P Value
	n or Mean	% or SD	n or Mean	% or SD	n or Mean	% or SD	
Age	76.92	9.53	82.14	13.02	78.59	12.25	<0.001
Age, N (%)							
Below age 60	40	9.9	5	2.6	45	7.6	<0.01
Age 60 and above	364	90.1	184	97.4	548	92.4	
Sex, N (%)							
Male	197	48.8	62	32.8	259	43.7	<0.001
Female	207	51.2	127	67.2	334	56.3	
Living Status, N (%)							
Married or living with someone	183	45.3	64	33.9	247	41.7	<0.01
Not married or living alone	221	54.7	125	66.1	346	58.3	
Average wait days to assess in home post-hospital discharge	9.00	12.7	21.2	10.7	13.2	12.8	
Medical Stability (CHESS)							
0 (Not at all unstable)	17	4.2	7	3.7	24	4	0.09
1-2 (Little - Some instability)	304	75.2	128	67.7	432	72.8	
3+ (Moderately - Highly unstable)	83	20.5	54	28.6	137	23.1	
Cognition (CPS)							
0 (Intact)	67	16.6	26	13.8	93	15.7	<0.001
1-2 (Border intact - mild impairment)	283	70	113	59.8	396	66.8	
3-4 (Moderate - Moderate Severe Impairment)	53	13.1	32	16.9	85	14.3	
5-6 (Severe - Very Severe Impairment)	1	0.2	18	9.5	19	3.2	
Care Urgency (MAPLe)							

1 - 2 (Low - mild)	35	8.7	15	7.9	50	8.4	0.412
3 (Moderate)	153	37.9	62	32.8	215	36.3	
4-5 (High - very high)	216	53.5	112	59.3	328	55.3	
Pain Scale							
0 (No Pain)	187	46.3	77	40.7	264	44.5	0.446
1-2 (Less than daily pain - daily pain not severe)	191	47.3	99	52.4	290	48.9	
3+ (Daily severe pain)	26	6.4	13	6.9	39	6.6	

7.2 Program Characteristics

During the period between 2014 and 2017, 479 stroke survivors were placed onto the community stroke rehabilitation pathway in the Waterloo Wellington health region. Each stroke survivor received an average of 30.5 rehabilitation home visits with an average time of 56 minutes per visit. The average length of stay on the community rehabilitation pathway in the community was 11.5 weeks.

On a weekly basis, participants received 2.63 rehabilitation visits per week which is aligned with the best practice recommendations of 2-3 visits per week for up to 8 weeks. 92.1% of the participants were visited by an occupational therapist in home within 24 hours of hospital discharge and 85.5% of the participants were involved with a discharge link meeting for transitional care.

Regarding the individual therapy disciplines, 100% of the participants received home visits from occupational therapists and physiotherapists with an average of 10.9 and 8.8 visits per person, respectively. Nearly two-thirds (65.7%) of the participants received rehabilitation by a speech language pathologist, with an average of 11.2 visits per person. Many (45.5%) of the participants received care by a social worker with an average of 3.54 visits per person. Lastly, 27.5% of the participants received visits by a dietitian with an average of 2.1 visits per person.

Refer to table 7.2 provides detailed information on program characteristics.

Table 7.2 Waterloo Wellington Stroke Rehabilitation in Community

Program Characteristics (April 2014 – April 2017)	Total # of Pathways	%	Total # of visits	Average Visits per Pathway	Average time per visit (mins)
Community Stroke Rehabilitation Pathway	479	100.00%	14735	30.49	56
Occupational Therapy Home Visits	479	100.00%	5611	10.98	57
Physiotherapy Home Visits	479	100.00%	4264	8.88	55
Speech Language Pathology Home Visits	315	65.76%	3552	11.28	54
Social Work Home Visits	218	45.51%	771	3.54	61
Dietetics Home Visits	132	27.56%	274	2.08	56
Initial OT home visit within 24 hours	441	92.07%			
Transitional Care meetings (Discharge link)	410	85.59%			
Duration: Average Length of Stay (LOS) on pathway	81 days	11.5 weeks			
Intensity: Average visits per week per pathway	2.63 visits/ week				
Best Practice Recommendations per week	2-3 visits				

7.3 Unadjusted Patient Outcomes

The following table provides a summary of unadjusted patient outcomes based on the assessments at baseline and at the 3 months follow up. Without adjusting for demographic variables or controlling for selection bias, improvements were observed in the functional and depression related status of participants upon the completion of rehabilitation therapy.

After completing the stroke rehabilitation pathway in the community, more participants reported themselves on the ADL hierarchy scale as independent than at the baseline stage (49.0% vs 37.6%, p<0.001), and fewer participants reported themselves as requiring supervision (30.2% vs 20.8%, p<0.001) or requiring extensive assistance due to total dependence (20.8% vs 23.8%, p<0.001).

On the IADL difficulty scale, a higher proportion of participants reported having no difficulty or minor difficulty in performing IADL activities at the 3 months follow up than at the baseline stage (23.3% vs 14.4%, p<0.001). Fewer participants reported having severe difficulty in performing IADL activities at the 3 months follow up than at the baseline stage (60.6% vs 68.1%, p<0.001).

Using the ADL long form scale that measures self-performance status in the areas of bed mobility, transfer, locomotion, dressing upper/lower body, eating, toilet use and personal hygiene, significant improvement in self-sufficiency was observed for participants at the 3 month follow up ($Mdn = 2$) than for participants at the baseline stage ($Mdn = 4$)($p < 0.001$).

In terms of depression related outcomes, depression was measured using the depression rating scale. Fewer participants at the follow up assessment indicated having symptoms of severe depression (score of 3 and above) than did participants at baseline (17.6% vs. 23.8%, $p < 0.01$).

Improvements in participants were also observed at follow up in other outcomes such as cognition, medical stability, care urgency levels, and pain. The following table 7.3 provides a complete list of unadjusted outcomes between the baseline and the 3 months follow up stages.

Table 7.3 Unadjusted Patient Outcomes based on interRAI HC's scales in stroke rehabilitation participants in community

N =404	Baseline	3 months follow up	P-value
ADL Hierarchy Scale			
0 (Independent)	37.6%	49.0%	<0.001
1-2 (Supervision required limited impairment)	38.6%	30.2%	
3+ (Extensive assistance required – total dependence)	23.8%	20.8%	
ADL Long Form Scale (median)	4.00	2.00	<0.001
IADL Difficulty Scale			
0 (No Difficulty – Minor Difficulty)	14.4%	23.3%	<0.001
1(Moderate Difficulty)	16.8%	16.1%	
2 (Severe Difficulty)	68.8%	60.6%	
Cognition Performance Scale			
0 (Intact)	16.6%	22.3%	<0.001
1-2 (Border intact – mild impairment)	70%	63.9%	
3-4 (Moderate – moderate severe impairment)	13.1%	12.1%	
5-6 (Severe – very severe impairment)	0.2%	1.7%	
Depression Rating Scale			
<3 (No or some symptoms of Depression)	76.2%	82.4%	<0.001
3+ (Possible or severe Depression)	23.8%	17.6%	
CHESS Scale (Medical Stability)			
0 (Not at all unstable)	4.2%	42.8%	<0.001
1-2 (Little – some instability)	75.2%	47.0%	
3+ (Moderately – Highly unstable)	20.5%	10.1%	
Pain Scale			
0 (No Pain)	46.3%	43.8%	<0.001
1-2 (Less than daily pain – daily pain not severe)	47.3%	50.0%	
3+ (Daily severe pain)	6.4%	6.2%	
MAPLe Scale (Predictor of admission to residential care)			
1-2 (Low – mild)	8.7%	19.6%	<0.001
3 (Moderate)	37.9%	31.7%	
4-5 (High – Very high)	53.5%	48.8%	

7.4 Adjusted Patient Outcomes using Propensity Scores

As described in section 5.1.6, propensity score methods were used for controlling for demographic confounders and selection bias. Firstly, propensity scores were calculated through a logistic regression model in which the treatment assignment variable (treatment vs. control) was regressed on seven baseline variables listed in Table 7.1. These baseline variables were age, sex, living status, cognition, pain, medical complexity (CHESS), and patient needs and urgency levels (MAPLe).

7.4.1 Regression Model Results

Several regression models were conducted to determine the association between treatment assignment (treatment group vs. control group) and the functional and depression related patient outcomes at the end of the rehabilitation pathway. The functional outcomes were examined using the 3 month follow up variables of the ADL Long form scale, the ADL hierarchy scale, and the IADL difficulty scale, whereas the psychosocial (depression) outcomes were examined using the 3 month follow up variable of the Depression Rating Scale.

ADL Long Form Scale

A multiple linear regression was carried out to predict the 3 months follow up ADL long form score based on an individual's treatment assignment (treatment or control), baseline ADL long form score, and the propensity score. The results of the regression indicated that the model explained 65.2% of the variance and that the model was a significant predictor

of follow up ADL long form score, $F_{(3,589)} = 367.2$, $p < 0.05$. A participant's predicted follow up ADL long form score is equal to $2.192 + 0.801$ (baseline ADL long form score) $– 2.185$ (propensity score) -1.057 (treatment group), where treatment group is coded or measured as $0 =$ Treatment and $1 =$ Control.

While adjusting for confounding by indication through propensity score and the baseline ADL long form scores, the treatment assignment variable (rehabilitation or control) was a significant predictor of lower follow up ADL long form scores ($\beta = -1.057$, $p < 0.05$). In comparison with the control group, the follow up ADL long form score decreased by 1.057 points in participants in the treatment group. The model predicts lower scores in ADL long form scale in the treatment group which means improved physical function in bed mobility, transfer, locomotion, eating, toilet use, personal hygiene, and dressing (upper and lower body). A decrease of 1 point in ADL long form scale is considered a clinically meaningful change (159). Appendix G contains the summary results of the multiple linear regression model.

ADL Self Performance Hierarchy Scale

A multinomial logistic regression was performed to model the relationship between the treatment assignment variable (treatment $= 0$, control $= 1$) and the follow up ADL hierarchy outcome variable ($0 =$ independent, $1 =$ limited impairment/supervision required, $2 =$ extensive assistance required). Additionally, the model was adjusted for baseline ADL hierarchy levels, and the propensity score variables. The conventional 0.05 criterion of statistical significance was used for all tests. The final model was improved upon the

intercept only model as the addition of predictor variables significantly improved the fit between the model and the data, χ^2 (8, N = 593) = 485.330, Nagelkerke R^2 = .631, p < 0.001. Significant unique contributions were made by the treatment assignment variable, χ^2 (2, N = 593) = 10.848, p < 0.05. After adjusting for baseline characteristics and treatment selection bias through propensity score adjustment, participants in the treatment group were three (2.99) times more likely to be independent than those in the control group at the 3 month follow up stage in comparison with the other outcome of "extensive assistance required or total dependence" (Adjusted OR = 2.99, 95% CI 1.53 – 5.86, p < 0.01). Refer to Table 7.5 for a summary of the multinomial logistic regression model results. Appendix H contains the full results of the model.

Table 7.4. – Multinomial Logistic Regression (ADL Hierarchy) – Analysis of 593 Stroke Survivors for functional outcome (ADL Hierarchy) by treatment assignment (Community stroke rehabilitation pathway vs. Traditional home care).

Outcome Variable	Predictor Variables	β	$SE\ \beta$	Wald's χ^2	OR	p	95% CI for OR	
							Lower	Upper
3 months follow up ADL Hierarchy 0 (Independent)	Treatment assignment 0 (Treatment)	1.097	.342	10.264	2.996	.001	1.531	5.861
	Treatment assignment 1 (Control)	.	.	.	.	.	.	.
3 months follow up ADL Hierarchy 1 (Supervision required/limited impairment)	Treatment assignment 0 (Treatment)	.459	.296	2.396	1.582	.122	.885	2.827
	Treatment assignment 1 (Control)	.	.	.	.	.	.	.
Test	Overall model evaluation			χ^2	df	p		
	Likelihood ratio test			485.33	8	0.000		

Note: The reference category in the 3 months follow up ADL hierarchy outcome variable is 2 = Extensive assistance required. The reference category in the treatment assignment variable is 1 = Control. Other predictor variables that were included in the model were propensity score variable and baseline ADL hierarchy variable.

IADL Difficulty Scale

A multinomial logistic regression was performed to model the relationship between the treatment assignment variable (treatment = 0, control = 1) and the follow up IADL difficulty outcome variable (0 = no difficulty, 1 = moderate difficulty, 2 = severe difficulty). Additionally, the model was adjusted for baseline ADL hierarchy levels, and the propensity score variables. The conventional 0.05 criterion of statistical significance was used for all tests. The final model was improved upon the intercept only model as the addition of predictor variables significantly improved the fit between the model and the data, χ^2 (8, N = 593) = 352.385, Nagelkerke R^2 = .547, p < 0.001. Significant contributions were made by the treatment assignment variable, χ^2 (2, N = 593) = 15.83, p < 0.001. After adjusting for baseline characteristics and for confounding by indication through propensity scores, participants in the treatment group were 3.8 times more likely to have no difficulty in IADL activities than those in the control group at the 3 months follow up stage (Adjusted OR = 3.83, 95% CI 1.77 − 8.25, p < 0.001). Refer to Table 7.6 for a summary of the multinomial logistic regression model results. Appendix I contains the full results of the model.

Table 7.5. – Multinomial Logistic Regression (IADL Difficulty) Analysis of 593 Stroke Survivors for functional outcome (IADL Difficulty) by treatment assignment (Community stroke rehabilitation pathway vs. Traditional home care).

Outcome Variable	Predictor Variables	β	SE β	Wald's χ^2	OR	p	95% CI for OR	
							Lower	Upper
IADL (0) – No Difficulty – Minor Difficulty	Treatment assignment 0 (Treatment)	1.343	.391	11.775	3.832	0.001	1.779	8.253
	Treatment assignment 1 (Control)	.	.	.	.	.	.	.
IADL (1) – Moderate Difficulty	Treatment assignment 0 (Treatment)	.902	.346	6.780	2.465	.009	1.250	4.860
	Treatment assignment 1 (Control)	.	.	.	.	.	.	.
Test	Overall model evaluation			χ^2	df	p		
	Likelihood ratio test			352.385	8	.000		

Note: The reference category in the 3 months follow up IADL difficulty outcome variable is 2 = IADL Severe Difficulty. The reference category in the treatment assignment variable is 1 = Control. Other predictor variables that were included in the model were propensity score variable and baseline ADL hierarchy variable.

Depression Rating Scale

To evaluate the depression related outcome, in particular depression, a binary logistic regression was conducted to model the association between the treatment assignment variable (treatment = 0, control = 1) and the follow up DRS outcome variable (0 = no symptoms of depression, 1 = significant symptoms of depression). The model was adjusted for baseline depression levels as well as the propensity score variable. The conventional 0.05 criterion of statistical significance was used for all tests. There was no statistically significant association found between treatment assignment and depression (Adjusted OR = 0.81, 95% CI 0.47 – 1.38, $p > 0.05$). Appendix J contains the summary results of the binary logistic regression model.

Table 7.6. – Binary Logistic Regression (DRS) - Analysis of 593 Stroke Survivors for depression related outcome (Depression Rating Scale) by treatment assignment (Community stroke rehabilitation pathway vs. Traditional home care).

Outcome Variable	Predictor Variables	β	SE β	Wald's χ^2	OR	p	95% CI for OR	
							Lower	Upper
Depression Rating Scale (0 = No Depression, 1 = Depression)	Treatment assignment 0 (Treatment)	-.205	.272	.570	.814	450	.478	1.388
Test	Overall model evaluation	χ^2	df	p				
	Hosmer and Lemeshow Test	4.898	8	.768				

Note: The reference category in the 3 months follow up DRS = 1 (>3 Symptoms of Depression). The reference category in the treatment assignment variable is 1 = Control.   Other predictor variables that were included in the model were propensity score variable and baseline ADL hierarchy variable.

Comparison of Results with and without propensity score adjustment

In all the models described above, the propensity score variable was included as a predictor variable in each model to adjust for confounding by indication. The following table compares two models for each scale outcome variable. The first model presents the odds ratio of each outcome variable without the propensity score adjustment, whereas the second model presents the odds ratio of each outcome variable when the propensity score is used as a predictor variable in the model.

Table 7.7 Comparison of Odds Ratio in models before and after propensity score variable adjustment using a total of 593 stroke survivors

Outcome Scale	Model	Predictor Variable (Treatment Assignment)	Model 1: Before Propensity Score Variable Adjustment				Model 2: After Propensity Score Variable Adjustment			
			OR	p-value	95% CI		OR	p-value	95% CI	
					Lower	Upper			Lower	Upper
ADL Hierarchy Scale 0 (Independent)	Multinomial Logistic Regression	Treatment Group	3.744	0.001	1.971	7.111	2.996	0.001	1.531	5.861
IADL Difficulty Scale (0) No Difficulty – Minor Difficulty	Multinomial Logistic Regression	Treatment Group	5.195	0.001	2.471	10.922	3.832	0.001	1.779	8.253
Depression Rating Scale (0 = No Depression (DRS <3), 1 = Depression (DRS>3+))	Binary Logistic Regression	Treatment Group	.804	0.399	0.475	1.376	.814	0.450	.478	1.388

Note: The reference category for the predictor variable treatment assignment is the control group.

7.5 Patient Experience Results

The 23-item Patient Experience Survey for Community based Rehabilitation (PESCR) was completed by stroke survivors or their caregivers/families in a home care setting after the 3-month completion of community rehabilitation. Of the 404 individuals that were asked to complete the PESCR, 134 (33.1%) participants responded to the patient experience survey including 112 (83.5%) stroke survivors and 22 (16.4%) family members/care givers. Participants responded to each item on a 5-point response scale which ranged between 1 (very dissatisfied) and 5 (very satisfied).

7.5.1 Construct Validity

A positive correlation ($r = 0.66$) was found between the global question (Question 1.11 in Table 7.9) and the overall score of questions in the patient experience section (Questions 1.1 to 1.10). See table 7.9 for mean and standard deviations for the global question and other patient experience items in the survey.

Table 7.8 Mean and SD for patient experience survey items (n=134)

#	Patient Experience survey items	Mean	SD
1.1	Access to patient's charts without any delay	4.48	0.69
1.2	Information was provided to family and friends	4.44	0.74
1.3	Felt safe when taking part in treatments	4.53	0.62
1.4	Involved in decision-making	4.24	0.99
1.5	Positive impact due to place of care	4.49	0.81
1.6	Participants knew what to expect next	4.37	0.78
1.7	Reached treatment goals	4.02	1.17
1.8	Treated with Courtesy	4.56	0.56
1.9	Physical pain was controlled	4.19	0.94
1.10	Likely to recommend	4.55	0.76
1.11	Overall Satisfaction (Global question)	4.48	0.80

7.5.2 Internal Consistency

There was strong internal consistency in the 5-point response scales with Cronbach's Alpha (α) = 0.91.

7.5.3 Survey Results

Participants were asked to provide feedback on 1) patient experience, 2) transitional care, 3) timeliness of access to care, 4) integrated care, and 5) returning to normal activities. In questions related to patient experience, the majority of the participants responded positively. Over 90% (122, 91.0%) of participants were satisfied with the care they received in the community. A majority of the participants (118, 88.1%) believed the care they received had a positive impact on their experience. One hundred and twenty (89.6%) participants felt that community rehabilitation team had access to the patient's clinical information they needed to initiate community rehabilitation without any delay. One hundred and fourteen (85.1%) participants strongly agreed or agreed that their chosen family and friends were given the information they needed about their care. One hundred and sixteen (86.6%) participants felt safe when taking part in treatments. Approximately 80% (106, 79.1%) of the participants felt involved in decision-making related to their care. 118 (88.1%) participants strongly agreed or agreed that the place where patients received care had a positive impact on their experience. Figure 7.6 illustrates proportion of participants that responded positively (strongly agreed or agreed) to all questions related to patient experience.
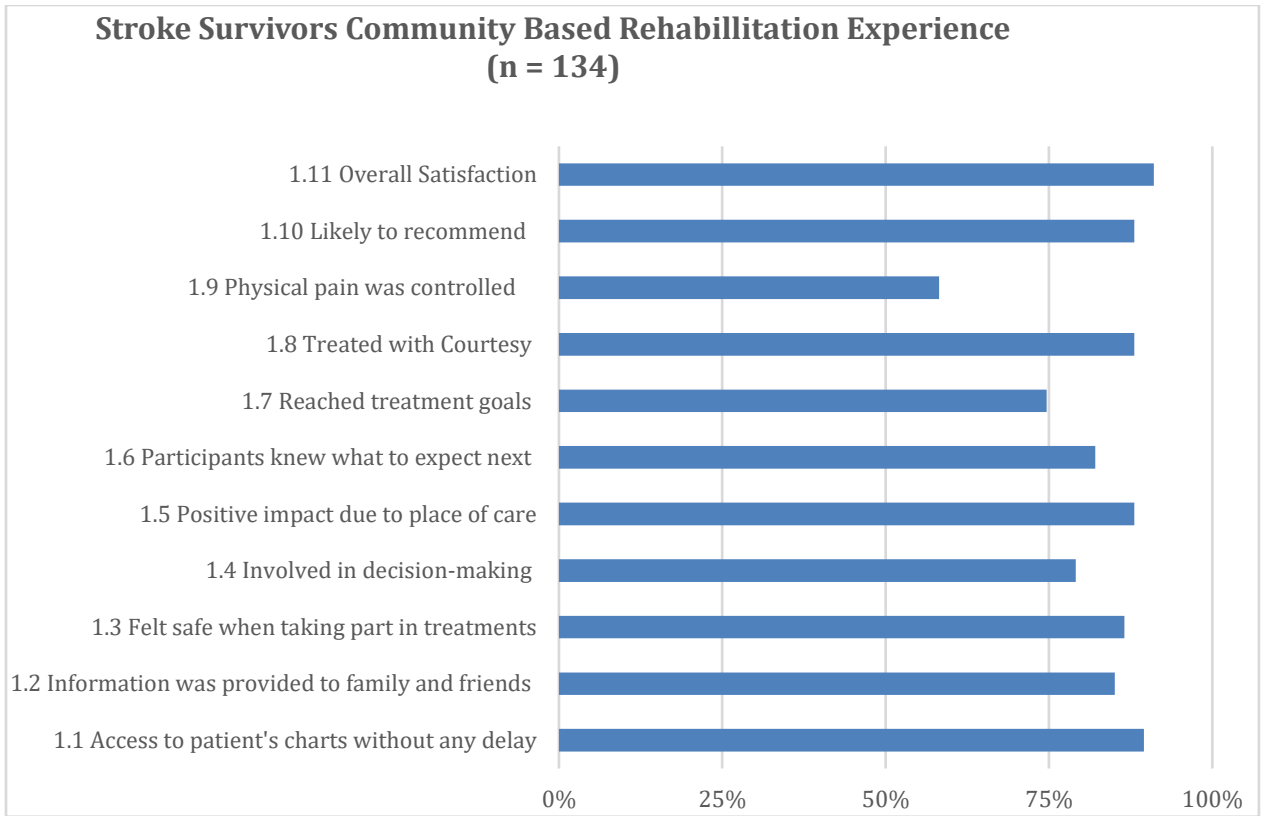
Figure 7.6 Stroke Survivor's Community based Rehabilitation Experience

In the area of transitional care, 108 (80.6%) participants strongly agreed or agreed that they received adequate information on community rehabilitation at the point of their hospital discharge. 116 (86.6%) participants strongly agreed or agreed that they felt confident at the time of discharge about knowing that help would be available in-home post-discharge. 108 (80.6%) participants knew what the next treatment plan was after hospital discharge. 64 (47.8%) participants strongly agreed or agreed that the same therapist that met the stroke survivors and/or their family members in hospital also visited in home after discharge.

In the section of timely access to care, 106 (79.1%) participants strongly agreed or agreed that stroke survivors were seen by a therapist in the home within 48 hours of hospital discharge. 104 (77.1%) participants felt it was helpful that the therapist made a community visit within 48 hours of hospital discharge. 98 (73.1%) participants knew they could speak to the community therapist or another member of the community team by phone during any day of a week.

In the section of integrated care, 114 (85.1%) participants felt that all the therapists that visited in home worked together as one team. 94 (70.1%) participants felt that they did not have to repeat information to the community team. 106 (79.1%) participants felt involved in decision-making related to their care.

In the section of returning to normal activities, 92 (68.7%) participants felt confident in managing their own care as a result of rehabilitation in the community. 70 (52.2%) participants felt they were able to return to participation in social activities. 62 (46.3%)

participants strongly agreed or agreed to returning to household activities such as cooking or gardening whereas 24 (17.9%) participants strongly disagreed or disagreed. The remaining participants responded with the options of neutral or other. Refer to Table 7.10for a complete list of survey items and participant's responses.

#	Items	Strongly Agree		Agree		Neutral		Disagree		Strongly Disagree	
		n	%	n	%	n	%	n	%	n	%
1.0	**Patient Experience**										
1.1	Community team had access to patient's clinical information to start rehabilitation without any delay	70	52.2%	50	37.3%	2	1.5%	4	3.0%	0	0.0%
1.2	My chosen family and friends were given the information they needed about my care	66	49.3%	48	35.8%	6	4.5%	0	0.0%	2	1.5%
1.3	Patient/Families felt involved in decision-making related to their care	64	47.8%	42	31.3%	8	6.0%	10	7.5%	2	1.5%
1.4	I always felt safe when taking part in treatments	70	52.2%	46	34.3%	2	1.5%	2	1.5%	0	0.0%
1.5	The place where patients received care had a positive impact on their experience	72	53.7%	46	34.3%	4	3.0%	0	0.0%	0	0.0%
1.6	Patients/Families knew what to expect about their care at the end of the community rehabilitation	60	44.8%	50	37.3%	4	3.0%	6	4.5%	0	0.0%
1.7	Patients reached the treatment goals at the end of the rehabilitation	50	37.3%	50	37.3%	4	3.0%	10	7.5%	8	6.0%
1.8	Patients were treated with courtesy	72	53.7%	46	34.3%	4	3.0%	0	0.0%	0	0.0%
1.9	My physical pain was controlled as well as possible	32	23.9%	46	34.3%	40	29.9%	2	1.5%	4	3.0%
1.10	Patients/families are likely to recommend this program to friends and family if they need the same care	80	59.7%	38	28.4%	2	1.5%	2	1.5%	2	1.5%
1.11	Overall, patient/families were satisfied with the care they received in the community	72	53.7%	50	37.3%	0	0.0%	0	0.0%	4	3.0%

Table 7.9 Stroke Survivor's Community Based Rehabilitation Experience - Results from 134 Stroke Survivors or family members

2.0	**Transitional Care**										
2.1	All the information related to stroke rehabilitation in the community was provided	58	43.3%	50	37.3%	4	3.0%	4	3.0%	6	4.5%
2.2	Patient/Families felt confident at time of discharge knowing help would be available in home	62	46.3%	54	40.3%	4	3.0%	4	3.0%	4	3.0%
2.3	Patient/Families knew what the next treatment plan was after discharge	56	41.8%	52	38.8%	4	3.0%	8	6.0%	8	6.0%
2.4	The same community therapist that met in the hospital also visited patient in the home	38	28.4%	26	19.4%	8	6.0%	22	16.4%	20	14.9%
3.0	**Timely Access to Care/Rehabilitation**										
3.1	Therapist from the community rehabilitation program visited patient's home within 48 hours of hospital discharge	66	49.3%	40	29.9%	2	1.5%	8	6.0%	4	3.0%
3.2	Patient/Families found it helpful that the therapist visited home within 48 hours of hospital discharge	68	50.7%	36	26.9%	2	1.5%	6	4.5%	4	3.0%
3.3	Patients/Families knew they could speak to the community therapist or another member of the team by phone seven days a week	50	37.3%	48	35.8%	10	7.5%	12	9.0%	4	3.0%
4.0	**Integrated Care**										
4.1	Patient/Families felt that all therapists that visited home worked together as one team	70	52.2%	44	32.8%	2	1.5%	8	6.0%	10	7.5%
4.2	Patient/Families did not have to repeat information to community rehabilitation staff	52	38.8%	42	31.3%	8	6.0%	16	11.9%	6	4.5%
5.0	**Returning to Normal Activities**										
5.1	Patient felt confident in managing their own care as a result of community rehabilitation	46	34.3%	46	34.3%	8	6.0%	6	4.5%	8	6.0%

| 5.2 | Patients felt they have returned to participating in household roles such as cooking or gardening | 26 | 19.4% | 36 | 26.9% | 6 | 4.5% | 12 | 9.0% | 12 | 9.0% |
| 5.3 | Patients felt they have returned to participating in social activities | 30 | 22.4% | 40 | 29.9% | 6 | 4.5% | 30 | 22.4% | 6 | 4.5% |

7.5.4 Open Ended Question Responses

The open-ended question responses were completed by 46 (34.3%) participants. Content analysis was used to classify comments into two main categories: program strengths and improvement opportunities. Major sub-categories of comments under program strengths included: overall positive experience (67.3%), supportive and encouraging role by community rehabilitation team (34.7%), caregiver and family relief (17.3%), and preference of receiving rehabilitation in home versus in an outpatient setting (13.1%). One participant who was a family member commented as follows, *"I think the program is excellent. After 68 days in the hospital, for my husband to come home and continue therapy at home made a big difference. It was important for his physical and emotional health. We really liked all the therapists, they were excellent. Social Work intervention was very helpful. My spouse received reassurance he needed".*

The sub-categories under improvement opportunities were client or families needing more physical therapy beyond 12 weeks (34.7%). For example, one respondent stated, *"Patient felt the team should have kept it going for longer than three months".* Other areas of opportunities included client or families feeling overwhelmed as community rehabilitation started too early post-hospital discharge (17.3%).. One respondent stated, *"Delay the first visit, i.e., OT, and have later within the first week. There was a lot of confusion at the beginning with all of the services i.e. therapists, PSWs, nurses. A list of all of the services, what the services would be doing and who is attached to the service at time of discharge i.e. Care Coordinator, PSW, Nrsg, Therapies, would be great".*

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issues related to consistency of receiving care by a Personal Support Worker (PSW) while being on a rehabilitation pathway (13.1%) as one respondent stated, "More consistency of PSWs i.e. showing up at the same time, showing up when scheduled (i.e. not missing visits). More consistency of PSWs completing the tasks they are supposed to be doing. That PSWs are mindful of the client's needs i.e. PSWs cue and not do for client.". Lastly, , there were also issues related to scheduling as the client or family did not always know when the next home visit would be made (8.6%).

Table 7.10 Open ended responses from stroke survivors or families (n=46)		
#	Categories	n
1.0	Program Strengths	
1.1	Overall Positive experience	31
1.2	Community rehabilitation played a supportive and encouraging role by motivating client	16
1.3	Caregivers and families felt relieved with the support in home	8
1.4	Client preferred in-home rehabilitation setting than outpatient	6
2.0	Improvement Opportunities	
2.1	Client or families felt they needed more physical therapy beyond 12 weeks	16
2.2	Client or families felt overwhelmed as community rehabilitation started too early	8
2.3	Consistency issues with Personal Support Workers (PSWs)	6
2.4	Scheduling – Families did not always know when home visits were scheduled	4

7.6 Comparison of the interRAI HC instrument with other tools

Completed before and after rehabilitation intervention, data using the interRAI HC's scales (ADL Long Form, ADL Short Form, and DRS) were available for 404 subjects. Data for other commonly used instruments in the stroke population such as BI and RNLI were available for 299 and 175 subjects respectively. Table 7.8 presents the sample statistics and the psychometric properties, including construct validity and responsiveness for the inter RAI HC's ADL and DRS scales as well as the BI and RNLI.

<u>Mean Levels</u>

Based on the data collected from the treatment group in the Waterloo Wellington region, statistically significant improvements (p <0.05) were found in mean levels from baseline to post-intervention of all three of the functional scales (inter RAI's ADL Long Form, ADL Short Form, and Barthel Index). However, as shown in table 7.8, a relatively small change in mean levels was observed for the ADL Long Form and the ADL Short Form in comparison with the mean levels for the BI scale. Statistically significant improvements (p<0.05) were observed in mean levels before and after the intervention for the interRAI HC's DRS scale and the RNLI scale.

Table 7.11 Sample Statistics and Psychometric Properties of ADL Long Form (ADL-7), ADL Short Form (ADL-4), Barthel Index, DRS, and RNLI

Items	Stroke Survivors Pre-Intervention	Stroke Survivors Post-Intervention
Mean (SD)		
ADL Long Form (ADL-7) (n=404)	5.8 (6.3)	5.2 (6.5)
ADL Short Form (ADL-4) (n=404)	2.8 (3.5)	2.6 (3.6)
Barthel Index (n=299)	71.1 (26.6)	81.2 (25.3)
DRS (n=404)	1.6 (1.9)	1.2 (2.0)
RNLI (n=175)	65.2 (19.1)	78.8 (16.3)
Proportion at floor		
ADL Long Form (ADL-7) (n=404)	0.29	0.36
ADL Short Form (ADL-4) (n=404)	0.46	0.49
Barthel Index (n=299)	0.01	0.01
DRS (n=404)	0.42	0.55
RNLI (n=175)	0.01	0.013
Construct Validity (Correlation coefficient, r (p-value))		
(ADL Long Form, BI) (n=260)	0.72 (<0.05)	0.70 (<0.05)
(DRS, RNLI) (n=131)	0.22 (<0.05)	0.21 (<0.05)
(BI, RNLI) (n=131)	0.37 (<0.001)	0.33(<0.001)
Responsiveness (SRM, 95% CI)		
ADL Long Form (ADL-7)	0.16	(0.06, 0.25)
ADL Short Form (ADL-4)	0.32	(0.25, 0.40)
Barthel Index	0.76	(0.65, 0.88)

DRS	0.18	(0.08, 0.28)
RNLI	0.78	(0.62, 0.92)
Responsiveness (ES)		
ADL Long Form (ADL-7)	0.09	
ADL Short Form (ADL-4)	0.25	
Barthel Index	0.37	
DRS	0.18	
RNLI	0.69	

Floor Effect

In comparison with BI, both of the interRAI HC's ADL scales (LF and SF) produced distributions that represented a high number of respondents with a score of zero. Unlike in BI, higher values represent greater difficulty in performing functional activities. To observe a floor effect, score distribution of interRAI HC's ADL scales (Long Form and Short Form) and DRS was compared with BI and RNLI respectively. As shown in Figure 7.1, 7.2 and 7.3, a greater variability of distribution was observed in the BI and the RNLI scores when compared with the ADL and DRS scales.
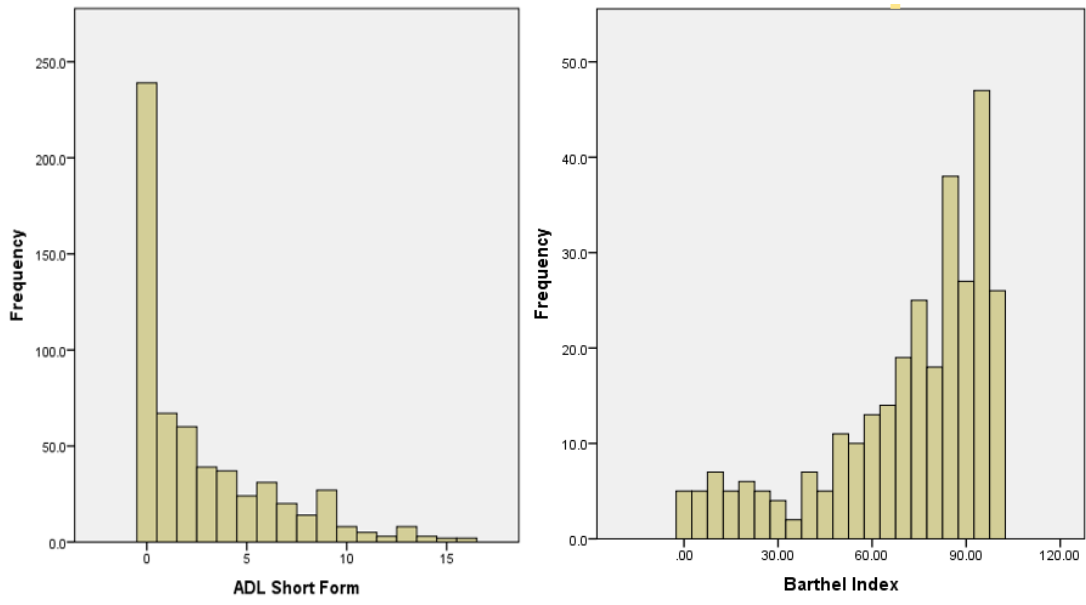
Figure 7.1 Distribution of pre-intervention scores for ADL Short Form and BI
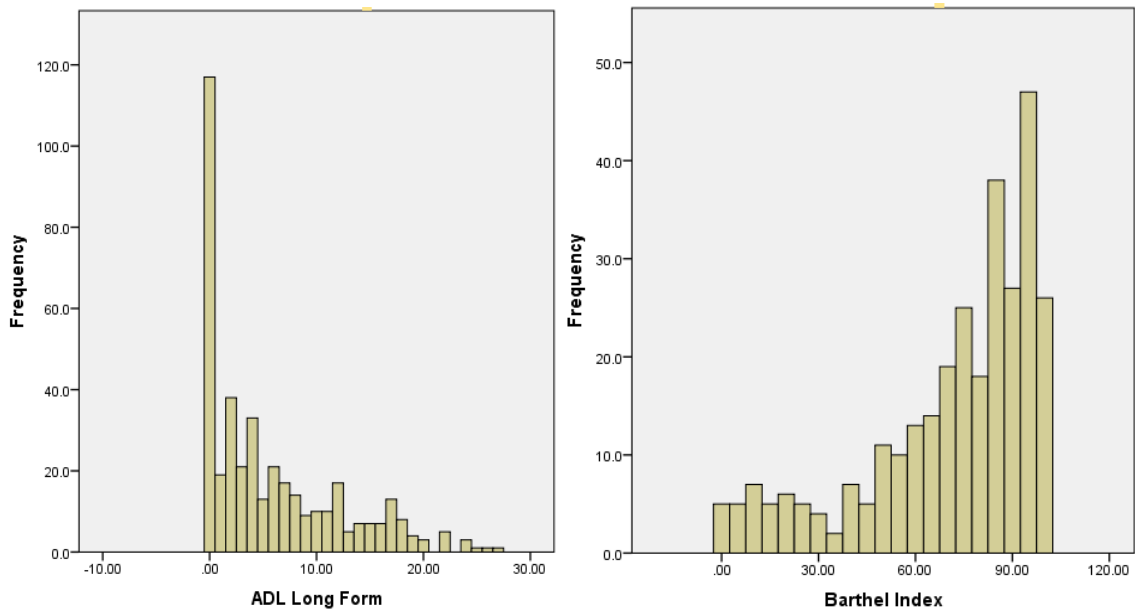
Figure 7.2 Distribution of pre-intervention scores for ADL Long Form and BI

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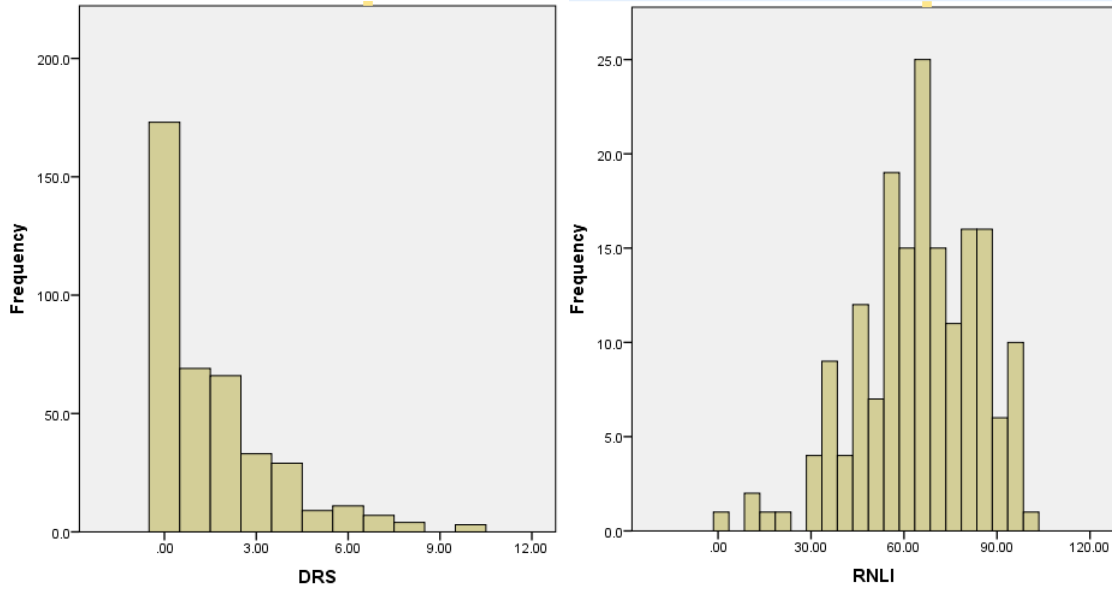
Figure 7.3 Distribution of pre-intervention scores for DRS and RNLI

Construct Validity

Construct validity was evaluated using correlations between the ADL Long Form and the BI and between the DRS scale and the RNLI. Agreement between the ADL Long Form and the BI were evaluated using the pearson's correlation coefficient. A strong correlation was found with statistical significance as the r was 0.72 ($p < 0.05$, n = 260) for the ADL Long Form with the Barthel Index. In comparing the DRS with the RNLI, a weak correlation was found as the r was 0.22 ($p < 005$, n = 131).
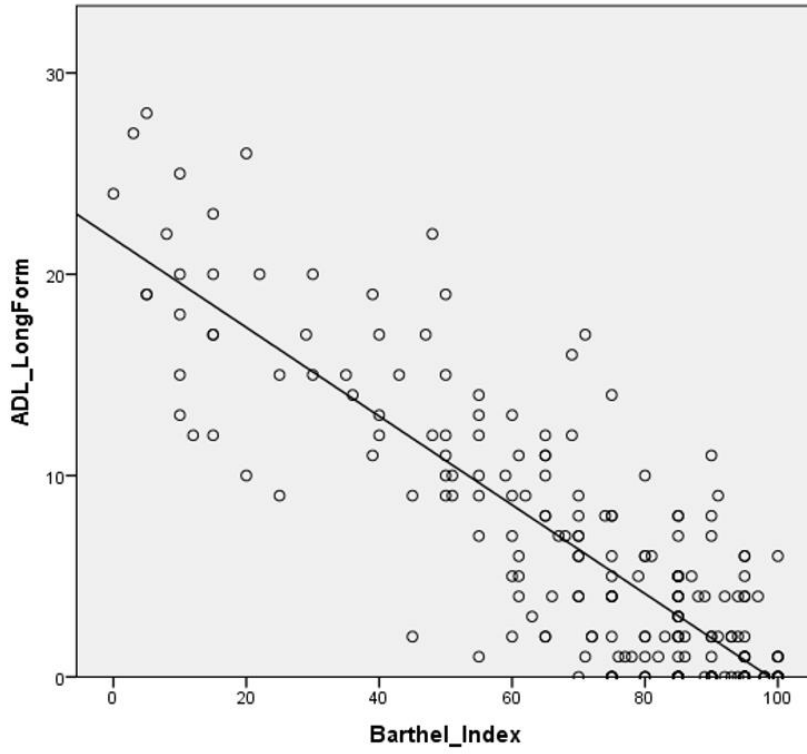
Figure 7.4 ADL Long Form (ranges 0-28) and Barthel Index (ranges 1-100), n = 260, r =

0.72
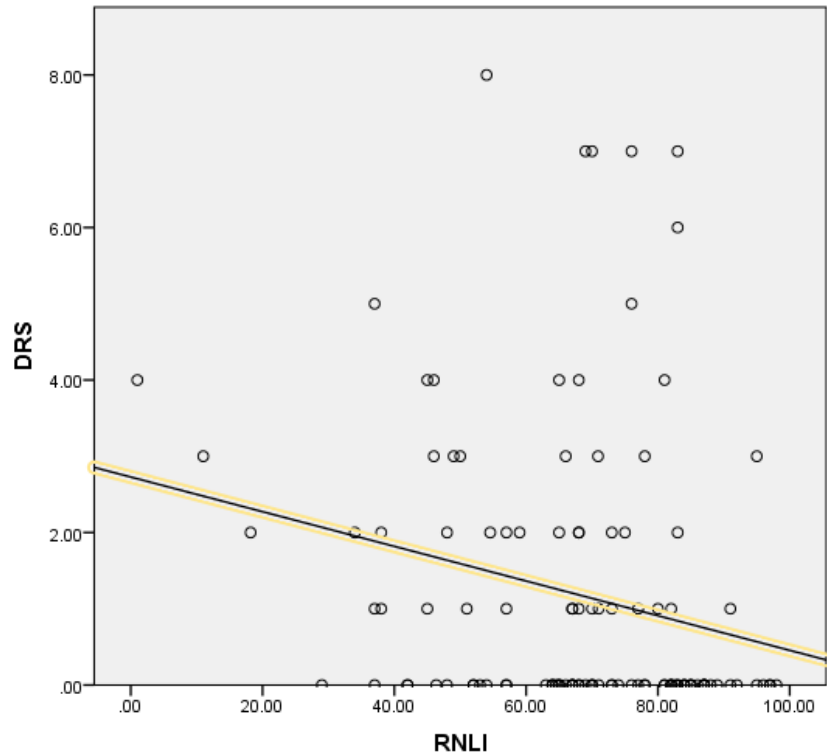
Figure 7.5 DRS (ranges 0-14) and RNLI (ranges 1-100), n = 131, r = 0.22

Responsiveness

The responsiveness data displayed in Table 7.11 was used to compare responsiveness statistics (SRM and ES) among the interRAI HC's ADL scales (Long Form and Short Form) and the BI. In this sample, the ADL Long Form that captures 7 ADL items (bed mobility, transfer, locomotion, eating, toilet use, personal hygiene, dressing upper body, and dressing lower body), had the lowest values for SRM and ES (0.16 and 0.09) among all the functional outcome scales.

In the shorter version of the ADL scale where the ADL items of bed mobility, transfer, dressing upper body, and dressing lower body are removed, the SRM and ES values were

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found to be slightly higher (0.32 and 0.25) but they were still not as high as the values for the BI (0.76 and 0.31).The SRM and ES values for the RNLI (0.78 and 0.69) were also higher than the DRS (0.18 and 0.18).

Chapter 8 Discussion

The objective of the study was to evaluate Waterloo Wellington's stroke community rehabilitation model of care through measuring patient health outcomes and patient experience. In addition, this study also examined the interRAI HC and other commonly used assessment tools in the stroke population.

The discussion is categorized into three parts in alignment with the research questions: 1) Patient Outcomes 2) Patient Experience and 3) Comparison of the interRAI HC with other instruments.

8.1 Patient Outcomes

Between 2014 and 2017, 479 stroke survivors received rehabilitation in a home care setting through a stroke community rehabilitation pathway after a discharge from an acute hospital or a rehabilitation centre. Participants remained on the community stroke rehabilitation pathway for an average of 11.5 weeks and received on average 2.6 visits per week by a community stroke rehabilitation team. The average time for a home visit was 56 minutes. This model of care was intended to meet the Canadian stroke rehabilitation best practices which recommend a minimum of 45 minutes per day of rehabilitation, 2-5 days a week, for up to 8-12 weeks after transitioning in community. Based on the provision of the above services, it is reasonable to suggest that this model of care was in alignment with the recommended stroke rehabilitation best practice guidelines.

The unadjusted pre and post results from inter RAI HC's functional scales (i.e. ADL Long Form, ADL Hierarchy scale and IADL Difficulty scale) and the depression rating scale show statistically significant improvements in functional and depression related outcomes after the completion of the 3-month stroke community rehabilitation pathway.

Since patients are generally expected to improve overtime after they are discharged from a hospital, we used a control group to compare outcomes that consisted of a cohort of stroke survivors that received traditional care (i.e., no rehabilitation in the community) elsewhere in Ontario during the same period.

The assignment of treatment is often influenced by an individual patient's characteristics and a systematic difference may exist between the treatment and control groups. Such was the case in our data as we saw significant differences in the characteristics between the treatment and control group. As reflected in Table 7.1, the treatment and control groups were significantly different for demographic characteristics such as age, sex, living status and clinical characteristics such as cognition. To account for such baseline differences, a propensity score method using covariate adjustment was used to adjust for the treatment selection bias and confounding factors. After propensity score covariate adjustment, regression models found statistically significant improvements in functional outcomes on the ADL Long Form, the ADL hierarchy scale and the IADL difficulty scale. There were no statistically significant improvements found between DRS and the treatment assignment variable.

Our study shows that after adjusting for the confounding variables and for the treatment selection bias through propensity score adjustment, participants in the treatment group had a reduction of 1.057 points on the ADL Long form scale. A change of one point in the interRAI HC's ADL Long Form scale is considered a clinically meaningful change (159) . This suggests that participants potentially gained functional improvements in performing ADLs related to bed mobility, transfer, locomotion, eating, toilet use, personal hygiene, and dressing (upper and lower body).

The participants in the treatment group were also 2.99 times more likely to be independent on the ADL Hierarchy scale than those in the control group at the 3-month stage post hospital discharge. The independence is based on the ability to perform ADL tasks related to personal hygiene, toilet use, locomotion, and eating. Additionally, participants in the treatment group were 3.8 times more likely to have no difficulty on the IADL Difficulty scale in meal preparation, ordinary housework, and phone use.

While extensive literature exists on the benefits of standalone rehabilitation for the stroke population in the community, limited Canadian studies exist that have evaluated functional and psychosocial outcomes based on a comparable level of rehabilitation intensity and duration. Our study showed functional improvements at the 3 month follow up mark however it is unclear whether stroke survivors would continue to hold these functional gains at the 6 month or the 12-month follow ups.. In another Canadian study that evaluated functional and psychosocial outcomes based on comparable levels of rehabilitation

intensity and duration, significant pre-post improvements in the functional and psychosocial outcomes in stroke survivors were found based on the scores from the FIM and the Hospital Anxiety and Depression Scale respectively (43).

Given that the participants in this study were generally older adults (mean age of 77), gains in physical independence could also potentially mean a reduction in utilization of personal support services in the home and community care sector. Our previous research on the personal support workforce has described in depth the need for personal support services for the ageing Canadian population (92).

In addition, we were only able to follow patients for 3 months post hospital discharge. Many stroke survivors were discharged from the community rehabilitation pathway at the completion of the intensive rehabilitation. While the evidence suggests significant functional gains (i.e., increased functional independence in performing ADLs and less difficulty in performing IADLs) after the intensive community rehabilitation, approximately 21% of participants continued to require extensive assistance in performing ADLs While the Canadian best practice rehabilitation guidelines suggest that stroke survivors should continue to receive rehabilitation in the community for up to 8-12 weeks (14), results from our study suggest that a sub-population may require additional rehabilitation. It is unclear whether this population needs additional rehabilitation beyond 12 weeks or only further intensification of rehabilitation during the first 12 weeks. Our patient experience findings which are discussed in detail later, suggest that 2-3 visits per week per therapy discipline can be overwhelming for some patients and families. Further

research is needed to understand this sub-population so we can establish the optimal duration and intensity of rehabilitation for this group.

Depression is an important outcome indicator for stroke reintegration (160). While the unadjusted depression related outcome results indicate that there were fewer participants with indicators of depression (DRS = <3) at the 3 month follow up (23.8% vs 17.6%, p <0.05), results were not statistically significant after adjusting for selection bias using the propensity covariate adjustment method.

This result was surprising as a multi-disciplinary intervention including social workers could have a considerable impact on the psychosocial outcomes of stroke survivors. A tentative explanation could be drawn here. Unlike occupational and physiotherapy visits, visits from a social worker were provided to only a 45% of stroke survivors in the program with an average of 3.5 visits per person. This is compared to the occupational therapy visits that were provided to all of the stroke survivors in the program with an average of 11.9 visits per person. While the Waterloo Wellington community model of care is in alignment with stroke best practices, each care plan is tailored to the individual's functional, cognitive and communication needs. Other studies have also found minor improvements in social functioning or health related quality of life (161, 162). A systematic review of randomized controlled trials found limited impact on mood, an important indicator of depression, based on multi-disciplinary (i.e. nursing, occupational therapy, physiotherapy, speech and language therapy, and social work) community-based interventions (40), although it is unclear what targeted interventions were being used to treat mood and depression. Our

study highlights the need to further explore the optimal levels of services that are needed to address depression.

Significant variability currently exists in the provision of publicly funded community-based rehabilitation services in Canada. Although the Canadian stroke best practices recommend for stroke survivors to continue to have specialized stroke rehabilitation in the community, provision of such services in Ontario is often dependent on resources and the availability of services instead on rehabilitation evidence (163). Evidence on best practices, poor local performance, sub-optimal patient experience and efforts of the government to reduce LOS became the drivers to initiate the implementation of evidence-based stroke rehabilitation in the Waterloo Wellington community of Ontario.

There are a number of strengths and limitations that are associated with this study. In terms of strengths, there was a high rate of engagement in the treatment group as approximately 84% of stroke survivors remained in the study and remained available for post-intervention follow up at 3 months. While this was an observational study, our study design approximated a randomized controlled trial by analyzing a control group and by using the propensity score method to adjust for treatment selection bias. A fundamental limitation of observational studies is that the treatment assignment is not random. Therefore, the demographic and clinical characteristics of patients could influence a clinician's treatment choice or the treatment's outcome, resulting in a bias when estimating treatment effects (164). The use of the propensity score method (covariate adjustment) in this study

strengthens the findings of our study as it controls for this treatment selection bias. It is also important to understand the performance of such propensity score methods so the researchers and clinicians can make more informed decisions when evaluating the findings of this study. The performance of each propensity score method is well described by Austin (2011) (165). In addition, a recent study in 2017 by Burden and colleagues examined the accuracy of all propensity score methods including covariate adjustment by comparing it with exact matching (164). They applied all propensity score methods to a previously reported real-life observational study and found that exact matching as well as all other propensity score methods produced similar results (164).

Additionally, we leveraged the interRAI HC to evaluate stroke survivor's before and after functional and psychosocial status during the process of their stroke recovery. The interRAI HC is a standardized comprehensive geriatric assessment tool that is used in the home and community care setting for assessment and care planning by trained regulated health professionals. Of the initial 479 participants, approximately 15% of participants were lost to follow up which could be explained by several reasons. It is possible that these participants did not go through an interRAI HC assessment after the completion of their program. For clients that did go through the initial and follow up interRAI HC assessment, , we did not experience a large amount of missing data (i.e. incomplete assessments) in client assessments and therefore the sample is likely an appropriate representation of the program population. In a systematic review on use of interRAI HC instrument for home care interventions, the interRAI HC instrument has proven to be a comprehensive tool for evaluating interventions in a home care setting (166). To our knowledge, this is the first

Canadian study that has evaluated a stroke rehabilitation model in a home care setting using the interRAI HC instrument. The embedded scales of interRAI HC, specifically the ADL long form, ADL hierarchy scale, IADL difficulty scale and the DRS can be considered for evaluating rehabilitation interventions and measuring outcomes for stroke population in a home-care setting. Although the particular program of Waterloo Wellington was implemented in just one region in Ontario, the interRAI HC is used all across Ontario for home care patients in Ontario. Therefore, the findings of this study can be used for generalizing expected outcomes in the stroke population in other regions. Additionally, this study has provided further basis to use interRAI HC as an evaluation tool for potential scale up of similar interventions elsewhere in Ontario and Canada.

The study also has several limitations. A large proportion of stroke survivors received rehabilitation in rehabilitation centres before they were transitioned to the community. In-patient rehabilitation settings use the FIM to assess the functional status of stroke survivors. Having a linkage with this data would have provided further insights to understanding the baseline characteristics of the treatment group. The results of this study are also limited to the stroke population who received rehabilitation in the home due to limited access to an outpatient rehabilitation. Our study design does not include a comparison of outcomes between the two care settings. Also, this study did not measure the impact of intensive rehabilitation on the utilization of health care services such as decreased readmission rates and lengths of stay in the hospital, However, previous research in a Canadian home care setting has concluded that similar interventions such as the one in our study can potentially reduce the LOS in hospital and readmission rates (163). Such cost benefit analysis is now

more important than ever as the government is making an effort to restructure the health care system based on "value for money" as a guiding principle (167).

An additional point to note is that, as the stroke rehabilitation program being tested in this study was confined to one region of Ontario (Waterloo-Wellington), the effectiveness of treatment might be considered a "Waterloo-Wellington effect". The propensity score was used to address this and aimed to include enough factors to differentiate program effects from geographic effects.

8.2 Patient Experience

In addition to patients' health outcomes and the clinical effectiveness of interventions, patient experience is being increasingly recognized as one of the pillars of quality in health care (168). Considering the fragmentation in the delivery of health care services, the measurement of patient experience can provide another perspective to evaluate new models of care, which is not readily available from patient health outcome measures (168).

In addition to the rehabilitation pathway home visits, this model of care also aimed to improve patient experience through supported discharge and transitional care, timely access to community rehabilitation, consolidated home care visits for all service disciplines (i.e., OT, PT, SLP, RD, SW) and linkage with primary care providers.

To measure patient experience of stroke survivors and families that received rehabilitation through the new model of care in Waterloo Wellington, the PESCR was locally developed to measure overall patient experience and specific aspects of care delivery (e.g., transitional care). This tool was administered in the home care setting with the stroke survivors at the completion of their 3-month long community-based rehabilitation.

The participants in this study that completed the PESCR represented a subsample from the treatment group and the characteristics of this group have been described earlier in section 7.1. In comparing the study sample's characteristics with of the general population of community dwelling residents receiving home care services in Ontario, both share similar demographic characteristics. Both groups have predominately older adults (65 years and above) although the median age of our study group is slightly younger (76.9 years vs 82.0 years). Both groups have predominately more women and those that are living alone (not married or widowed) (169).

Patients that completed the PESCR reported high levels of positive experience with the overall scores ranging from 75% to 90% of the total scores. It is possible that some high levels of satisfaction could be attributed to a generally positive experience due to improved functional outcomes and quality of life. While the overall patient experience as well as specific aspects of care delivery such as transitional care, timely access to rehabilitation, and integrated care received high positive scores, scores related to participant's ability to return to their normal activities were slightly lower, ranging from 46% to 69%. These

results might indicate that although participants have improved functional outcomes, they might not have resumed full physical recovery.

The open-ended responses also yielded many positive comments. The participants appreciated the community rehabilitation team's role in motivating participants through encouragement and support. Although the stroke community model had no specific intervention (e.g. caregiver relief support) in place, the results found that caregivers also felt relieved knowing that there was support available in home after hospital discharge. Patient experience data were gathered from caregivers only when a stroke survivor was not able to share his/her own experience. This factor is a noteworthy limitation of this study since the informal caregivers contribute significant amounts of unpaid care to the older family members and those with medical complexities (170). A number of participants also suggested that the best environment in which to receive physical therapy was in home.

Despite the positive overall responses, the PESCR was able to capture negative encounters in item level scores and open-ended responses. The open-ended responses provided several improvement considerations for service delivery. A significant number of participants felt that the therapy should have continued beyond the 3-month period post hospital discharge despite the fact that the care coordinators transitioned stroke survivors to other rehabilitation support services in the community such as the outpatient rehabilitation programs or exercise programs for stroke survivors at the local YMCAs. The responses also suggested that clients and families preferred a longer but less intense physical therapy. Some respondents also felt overwhelmed when the community rehabilitation was initiated

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within 48 hours of hospital discharge. The respondents noted that community rehabilitation started too early as stroke survivors and families needed time for adjustment as they transition back in home. Although care provide by PSWs was not part of the stroke community rehabilitation pathway, many respondents believed they were part of the same team. Responses reflected what is already known in the literature about issues related to consistency of care provided by PSWs (92). Lastly, communication could be further improved between stroke survivors/families and community workers for scheduling home visits. The participants noted that they did not always know when the next therapy home visit was scheduled.

As part of this study, we also tested the PESCR's psychometric properties, including its construct validity and internal consistency reliability. There is a moderate to strong correlation between the global question and the overall scores indicating strong construct validity. The high internal consistency suggests that the PESCR's reliability is acceptable whereas the high response rate suggests that it can be considered for future use in appropriate settings for its feasibility. The results of this study are also consistent with the findings for the WatLX instrument, a measure of patient experience in ambulatory rehabilitative care settings (17). Both the WatLX and the PESCR resulted in similar levels of internal consistency (WatLX: $\alpha= 0.95$ vs PESCR: $\alpha= 0.91$), For construct validity, both instruments had a moderate to high correlation although WatlX had a slightly higher correlation value than the PESCR (WatLX: $r =0.73$ vs PESCR: $r=0.66$). The results from this study suggest that the PESCR measure is both valid and reliable.

A strength of this study is the self-reported data, particularly the open-ended responses as they provide specific insights into the delivery of a community-based rehabilitation model for stroke survivors. However, results should be interpreted with caution as the response rate was only 33% and a large proportion of stroke survivors that received rehabilitation through this model of care did not participate in the survey. A higher response rate that included more participants particularly those with severe stroke or with cognitive impairment could have affected the findings of this study. Another limitation of this study is that more information is not available on participant's characteristics such as stroke severity (mild, moderate, severe) and whether a participant had any cognitive impairment. A breakdown of patient experience survey results by these types would have provided further insights into the experiences of participants.

8.3 Comparison of the interRAI HC with other instruments

In this study, we compared the interRAI HC's ADL (Long Form and Short Form) and DRS scales with other commonly used assessment scales (BI and RNLI) for the stroke rehabilitation population in the community. This comparison was primarily conducted for psychometric properties, including construct validity and responsiveness.

Using the pre-post design of the study, both ADL scales (Long Form and Short Form) as well as the BI were able to detect change based on the mean change levels. In terms of responsiveness, the BI was more responsive than the ADL Long Form. The responsiveness

increased with the shorter version of the ADL scale (Short Form) where the ADL items of bed mobility, transfer, dressing upper body, and dressing lower body are no longer taken into account. However, the shorter form of the ADL scale still had a much lower responsiveness when compared with the BI. In comparing the responsiveness between the DRS and the RNLI, the DRS also had a much lower responsiveness than the RNLI.

The low levels of responsiveness could be explained by the floor effect observed in the ADL scales at the pre-intervention measurement level. The proportion of pre-intervention scores at floor for the interRAI scales was much higher than for the BI and RNLI (0.29 and 0.42 vs 0.01 and 0.01, $p < 0.05$). Approximately one third of participants had a score of zero on the ADL or DRS scales (indicating minimum impairment or depression) suggesting that the scales would have no ability to further capture functional or psychosocial gains after the intervention. There was also not enough variability in the observations as the distribution of scores was skewed to the right (as shown in figures 7.1 – 7.3) and hence the distribution cannot be considered normal. Since responsiveness is the ability to detect and measure changes over time, the lack of variability in the range of observations as well as the high proportion of respondents scoring at the floor level could explain the lower levels of responsiveness in the inter RAI's ADL and DRS scales.

A previous Canadian study in a complex care setting that compared the interRAI HC's ADL scales with the FIM in a geriatric population also found the ADL scale to have less responsiveness than the FIM (101). The results of our study suggest that the ADL and DRS

scales from the interRAI HC instrument perform well in subpopulations with significant impairment, such as those who scored high on ADL scales, but these scales have less discriminatory power among those with less physical or psychosocial impairment.

Correlations were used to assess the construct validity between the ADL Long Form and the BI. Results showed that the ADL Long Form was highly correlated with the BI in our study which suggests that the ADL Long Form and the BI both measure the concepts or constructs that they intend to measure. A previous study by Landi et al (2000) compared the correlation between the Minimum Data Set (MDS) – ADL Scale (now known as interRAI) and the BI based on 95 participants in a home care setting in Italy (102). Results were similar to the results found in our study as the ADL scale and BI were highly correlated (102). This highlights an important clinical implication for the front-line healthcare professionals as they use the assessment scales in the stroke population. The results suggest that both scales, ADL Long Form and the BI accurately measure their respective intended constructs which is primarily the patient's functional status. Therefore, health care professionals could use either of the two scales to assess functional ability and could potentially consider both scales as interchangeable as long as they keep in mind the strengths and limitations of each scale. The BI is a standalone instrument and may not be part of the routine practice by health professionals in a home and community care environment whereas the interRAI HC's ADL Long Form scale is part of the broader comprehensive assessment but may not be as responsive in detecting change for subjects with minor functional impairment as the BI.

Results from the correlation analysis between the DRS and the RNLI found that the scales were not correlated with each other. The RNLI is a commonly used as a quality of life indicator in the stroke population (145). It has been previously compared for construct validity with other depression tools such as Hospital Anxiety and Depression tool (145). A few previous studies that measured the correlation of DRS with other depression related scales in a palliative population found similar outcomes (171, 172). A study by Koehler et al (2005) compared the DRS with a geriatric depression scale and found that the two were not correlated with one another although both scales were found to be reliable for their intended construct (171).

Our objective was to compare the RNLI with the interRAI HC's DRS to identify whether they evaluate similar aspects of a subject's depression or items related to quality of life. The fact that the DRS and RNLI are not correlated with each other implies that they evaluate different aspects of an individual's psychosocial symptoms. In order to be categorized with having symptoms of depression or deemed as depressed on the DRS, the subject would have to exhibit persistent anger, make negative statements, express unrealistic fears, complain about health repetitively, and show sad, pained expressions and have tearfulness in the three days prior to the assessment (120). The RNLI asks subjects if they are able to participate in recreational activities and participate in social activities with friends and family, if they spend most of their days occupied in work that is meaningful to them, and if they are comfortable with their personal relationships. It seems conceivable that the RNLI seems to measure the individual's overall mindset (in response to recent

change in living situation) rather than the presence of major symptoms of depression. Therefore, we can conclude that the RNLI and DRS evaluate different aspects of an individual's psychosocial traits and cannot be equivalent or interchangeable.

The interRAI HC instrument has been mandated by the Ontario government to be used as a comprehensive geriatric assessment tool for older adults in the home and community care setting. This also includes the stroke population who continue to receive community-based rehabilitation after they are transitioned to home from a hospital or a rehabilitation centre. While the interRAI HC has been used in the home and community care sector for over a decade, its operational use has not been optimized in a way where information is shared and understood by all the home care agencies involved in patient care (19). As a result, duplication of effort and resources could potentially exist as community workers conduct similar assessments using the BI and RNLI to assess functional and psychosocial outcomes instead of leveraging existing information from the interRAI HC. A number of studies have cited a lack of understanding of the interRAI HC and its outputs and the lengthiness of the instrument as the barriers for service provider agencies to utilize the interRAI HC information (18, 19). Although a number of studies have previously tested the interRAI HC for validity and reliability, to our knowledge, this is the first Canadian study that has compared the functional and psychosocial assessment interRAI HC scales in a home care setting for the stroke rehabilitation population.

Results from this study should be interpreted with caution as several limitations exist. Since this study was part of a broader evaluation study that measured patient outcomes and patient experience, our analysis had few participants that declined in their functional status. Therefore, we were only able to evaluate the ability of instruments to detect improvements rather than decline. These findings are still relevant in this population as stroke rehabilitation patients are generally expected to improve as a result of their rehabilitation treatment.

Data collection for the interRAI HC, BI and RNLI instruments was conducted by trained regulated health professionals however they were unblinded and may have been biased to assess stroke rehabilitation patients more positively at the 3 months follow up. Analysis was conducted based on the data from the participants that were part of the rehabilitation group. While we had access to the interRAI HC data from a control group who received traditional or no care elsewhere in Ontario, data for the BI and RNLI assessments were not available for this group.

Lastly, validation studies require data for the assessment scales to be normally distributed across the entire range of the assessment scores (102). While the data from the BI and RNLI were normally distributed, data from the ADL and DRS scales were skewed to the right as a large proportion of participants had little impairment in functional or psychosocial traits. Therefore, limiting our analysis among those with higher impairment levels.

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The results of this study have important implications for practice, policy and future research. Our results suggest that the Waterloo Wellington's community rehabilitation model where intensive and timely in-home rehabilitation of 2-3 visits per week per discipline for up to 12 weeks, is provided to stroke survivors after hospital discharge can significantly contribute towards improvements in functional independence and patient experience. Such alignment of community stroke rehabilitation services in Waterloo Wellington with the recommended stroke best practice guidelines should be continued. This model should also be considered in developing stroke community rehabilitation services in other parts of Canada where such in-home services or outpatient rehabilitation services are not yet available. Since the interRAI HC is currently being used as a standardized tool for assessment and care planning in home care setting, its use should be optimized to assess and evaluate functional outcomes in the stroke population. Further research should be conducted to evaluate long-term outcomes for stroke survivors who receive intensive rehabilitation in the community, with additional consideration given to impacts for caregivers. Future research should also be conducted in comparing health outcomes between those who received in-home rehabilitation versus outpatient rehabilitation. Future evaluations could include outcomes on health services utilization (e.g. hospital re-admissions), and cost-benefit analysis.

8.4 COVID-19 and its implications on stroke care

The COVID-19 pandemic has surfaced as one of the biggest public health challenges in this century (173). It has affected all parts of the world and has presented major

implications for stroke care. Patients with stroke are vulnerable as they are susceptible to developing complications and death when suffering with the COVID-19 infection (174). Stroke services worldwide including Canada are facing significant pressures so outcomes of patients with stroke but without COVID-19 maybe worse than in normal times (174).

The World Stroke Organization (WSO) has reported significant impacts of the pandemic on acute stroke services in many countries (174). Many neurology and stroke beds including intensive care units as well as health care professionals (physicians, nurses and other stroke related health care workers) have been reallocated to look after COVID-19 patients (174). Through a multi-national survey, the WSO has also reported a sharp reduction in acute stroke cases in many countries such as Chile, Colombia, Iran, Greece, UK, Belgium, and Italy. The reduction in cases could likely come from patients with milder stroke with fears of acquiring the COVID-19 infection if they find themselves in a hospital setting.

Health systems in Canada also face similar challenges as they continue to cope with an increasing number of COVID-19 infections and the constraints related to containment measures such as physical distancing, quarantine, and personal protection (173). The observation of worldwide decrease in number of individuals with milder stroke symptoms visiting emergency department raises new concerns as it carries a higher risk of a recurrent stroke event with more severity and long lasting impact on physical, social and cognitive functions of stroke patients (173). The recent literature on stroke has recommended to

continue with the message that stroke is a medical emergency and requires an urgent response and such facts are not changed by the COVID-19 pandemic.

There is also evidence that the COVID-19 pandemic has had a negative impact on access to rehabilitation care (173). Stroke survivors that are discharged directly to the community may get limited access to specialized community-based stroke rehabilitation. It is also possible that those stroke survivors who receive inpatient stroke rehabilitation may have a reduction in their length of stay (173).

It is important that health policy makers and planners continue to recognize stroke rehabilitation as essential for people to achieve optimal levels of physical and social functioning following their stroke event (173). Rehabilitation programs need to continue providing evidence-based care for stroke patients. In the context of the COVID-19 pandemic, the front-line rehabilitation teams need to ensure they are well educated on the use of Personal Protective Equipment (PPE) and that they adhere to infection control procedures while having direct contact with stroke patients during their therapy sessions (173).

The use of telerehabilitation has an emerging importance during the COVID-19 pandemic. It is considered to be a well-accepted and effective method of providing community-based rehabilitation services (173). Telerehabilitation can be considered for family conferences at discharge, safety assessment of home environment, education to family and caregivers, skills training and patient monitoring (173). It is also important to recognize the barriers

associated with telerehabilitation. Stroke care programs and stroke care providers should use telephone visits or involve family members to address barriers such as access to reliable internet connection, access to electronic devices or physical or cognitive impairments to use technology (173).

Chapter 9 Conclusion

While significant progress has been made at national and provincial levels to achieve best possible stroke care in Canada, many gaps exist between best practices and current practices in stroke care (59). Initiatives led by the Canadian Stroke Strategy and the need to reduce ALC rates mobilized the provinces and regional authorities to deliver best practice stroke care (59). In order to achieve outcomes from implementing best practices in the acute care and in-patient rehabilitation sectors, timely rehabilitation in the community after hospital discharge is critical (9). Over the last few years, significant efforts had been made to implement a community rehabilitation model of care for stroke patients in the Waterloo Wellington region of Ontario. Our study attempted to evaluate patient outcomes based on a rehabilitation pathway of 2-3 visits per week per discipline for up to 12 weeks post-hospital discharge. Patient experience was also evaluated in addition to a comparison of psychometric properties of commonly used assessment instruments in the stroke population.

By adjusting for baseline characteristics such as age, sex, living status, cognition, and health instability, as well as for the selection bias through the use of propensity score method, the positive outcomes and positive experience in stroke patients can be attributed to the Waterloo Wellington's rehabilitation model of care.

The PESCR was shown to have acceptable levels of reliability and validity in the home care rehabilitation setting. The participants had a positive experience overall as well as for specific aspects of care delivery. The lower scores in returning to normal activities suggest that some participants might continue to have unmet needs of functional independence.

The interRAI HC's ADL Long Form scale and BI are strongly correlated and seem to be evaluating the same aspects of an individual's functional status. However, the ADL Long Form is not as responsive as the BI particularly in the subpopulation of the stroke population with no or minimum levels of impairment. The DRS and RNLI are not correlated with each other and appear to measure different aspects of an individual's psychosocial outcomes. The interRAI HC's ADL Long form and DRS are valuable scales that are already part of the existing bundle of standardized geriatric assessments in home and community care. Information collected using these assessments can be useful in the stroke rehabilitation population. It is hoped that this research brings us one step closer to understanding how assessment of a patient's health care needs from different instruments can be leveraged among the community providers in order to optimize the limited resources in our health care system.

The results of this study suggest that a community-based rehabilitation program that is multi-disciplinary, timely, well-coordinated and follows the recommended best practices of rehabilitation intensity (2-3 rehabilitation visits per week per discipline for up to 12 weeks), could achieve significant improvements in patient outcomes during the first three

months after hospital discharge among a large proportion of stroke survivors who are reintegrating back in the community. Additional research is warranted to understand further rehabilitation needs including the optimal length of service delivery for stroke survivors that require additional help beyond the initial 12-week period of reintegration into community. Such findings are important when the availability of such services is dependent on limited publicly funded resources.

The COVID-19 pandemic has dramatically altered the processes associated with patient access and stroke care. However, it is important to ensure that the best practice standards and comprehensiveness of stroke care are preserved. The risk of moving away from such standards could result in higher rates of recurrent strokes and ongoing disabilities related to physical and social function (173). Such impact will only add more burden on a health care system that is already over-stressed.

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  b) Licensee has full power and authority to enter into this Agreement and any other documents to be executed and delivered by it pursuant to this Agreement; and

  c) this Agreement, when executed and delivered, will be a valid and binding obligation of the Licensee, enforceable against it in accordance with its terms.

8. INDEMNITY

8.1.   Licensee hereby indemnifies and holds harmless Licensor, its officers, directors, and employees for any losses, damages, costs, including solicitor and client costs, suffered or incurred by Licensor, its officers, directors, or employees for any third party claims related to Licensee's dissemination of the Licensor Work.

8.2.   Licensor shall indemnify and hold Licensee harmless against any and all claims made against it for any third-party intellectual property infringement caused by the use of the Licensor Work by Licensee.

9. NOTICES

9.1. Notices made pursuant to this Agreement shall be made in writing and delivered to the following addresses:

> **For:** **Heart and Stroke Foundation of Canada**
>
> *By email To:* Dominique Mongeon, Intellectual Property Manager
> dominique.mongeon@heartandstroke.ca
>
> *And to:* Emily Sternberg, General Counsel
> emily.sternberg@heartandstroke.ca
>
> *By Post to:* Heart and Stroke Foundation of Canada
> 110-1525 Carling Ave
> Ottawa, Ontario K1Z 8R9
> Attn: Dominique Mongeon, Intellectual Property Manager
>
> *And To:* Heart and Stroke Foundation of Canada
> 2300 Yonge Street, Suite 1300
> Toronto, Ontario M4P 1E4
> Attn: Emily Sternberg, General Counsel
>
> **For:** **Arsalan Afzal, BHSc, MHSc, PhD Candidate**
>
> *By email to:* Arsalan Afzal, BHSc, MHSc, PhD Candidate
> arsalan.afzal@uwaterloo.ca
>
> *By Post to:* Arsalan Afzal, BHSc, MHSc, PhD Candidate
> School of Public Health and Health Systems
> University of Waterloo

Any such notice shall be deemed effective:

(i) on the business day following delivery, if delivered personally; or

(ii) on the day of sending if sent by facsimile transmission or electronic mail during normal business hours of the addressee on a business day and, if not, then on the first business day after the sending thereof.

10. GENERAL PROVISIONS

10.1. No modification or variation of this Agreement shall be valid unless made in writing and executed by the Parties in the same manner as this Agreement.

10.2. This Agreement may be executed in counterparts and delivered by electronic transmission and the counterparts together shall constitute an original.

10.3. This Agreement shall be governed by the laws of the Province of Ontario and the federal laws of Canada applicable therein.
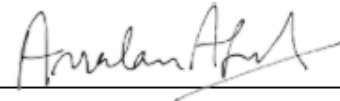
10.4. This Agreement will be binding upon and will enure to the benefit of and be enforceable by each of the Parties, their respective successors and permitted assigns. No Party may assign its rights and/or obligations under or transfer any of its interest in this Agreement without the prior written consent of the other Party, which shall not be unreasonably withheld or delayed.

10.5. This Agreement embodies the entire agreement of the Parties with respect to the License to use the Licensor Work and no other undertakings or agreements, verbal or otherwise, exist between the Parties regarding this Agreement, except as expressly set out herein.

IN WITNESS WHEREOF this Agreement has been executed by the Parties as of the Effective Date.

**HEART AND STROKE
FOUNDATION OF CANADA**

Name: Dominique Mongeon
Title: Intellectual Property Manager

Name: Arsalan Afzal
Title: BHSc, MHSc, PhD Candidate

Canadian Institute for Health Information

Thank you, Mr. Arsalan Afzal, for your request to use and adapt the following Canadian Institute for Health Information ("**CIHI**") work:

- Figure 2, "Most Common Pathways for Stroke Patients" found on page 6 of Pathways of Care for People With Stroke in Ontario found at https://secure.cihi.ca/free_products/Pathways_of_care_aib_en.pdf (the "Work").

Your email informed us that you wish to use and adapt the Work in your PhD thesis chapter for educational purposes (the "**Purpose**").

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Appendices

Appendix A interRAI HC Health Outcome Indicator Description

Activities of Daily Living (ADL) Short Form: is a summary measure of the client's ability to perform ADLs and is based on four ADL items (Early loss – personal hygiene, Middle loss toileting – toilet use, Middle loss movement – locomotion, Late loss – eating)

Activities of Daily Living (ADL) Hierarchy: is a measure of ADL performance and categorizes ADLs according to stages at which they can no longer be performed. The aim of the scale is to reflect the disablement process rather than to simply sum impairment of function.

Activities of Daily Living (ADL) Long Form: is a summative scale capturing 7 of the ADL items (Bed mobility, Transfer, Locomotion, Eating, Toilet Use, Personal Hygiene, Dressing Upper body, Dressing Lower body).

Changes in Health End-Stage Disease and Signs and Symptoms of Medical Problems (CHESS): This scale was developed to detect frailty and instability in health. The CHESS attempts to identify individuals at risk of serious decline and can serve as an outcome where the objective is to minimize problems related to frailty (e.g., declines in function) in the elderly population.

Cognitive Performance Scale (CPS): is a hierarchical index used to rate the cognitive status of clients, and has been validated against the Mini Mental State Examination (MMSE) and the Test for Severe Impairment.

Depression Rating Scale (DRS): The DRS can be used as a clinical indicator of depression, and is based on 7 items embedded within the MDS-HC. It may be used as a potential screening instrument for depressive disorders. This scale is validated against the Hamilton Depression Rating Scale and the Cornell Scale for Depression.

Instrumental Activities of Daily Living (IADL) Difficulty: is a hierarchical index that measures difficulty with three IADLs items (Meal preparation, Ordinary housework, Phone use)

Instrumental Activities of Daily Living (IADL) Involvement: This scale is based upon a sum of all 7 self-performance IADL items (Meal preparation, Ordinary housework, Managing finances, Managing medications, Phone use, Shopping, Transportation)

Method for Assigning Priority Levels (MAPLe): MAPLe is an algorithm derived from the RAI HC. It predicts a client's risk of adverse health outcomes. Clients at the very high MAPLe level are at risk of adverse outcomes, based on his/her greater problems in cognition, ADL function and/or Behaviour.

Appendix B : Patient Consent Letter

Title of Project: *Evaluation of Stroke Community Rehabilitation Program*

Researchers:

Arsalan Afzal, Student Investigator, School of Public Health and Health Systems, University of Waterloo

Paul Stolee, School of Public Health and Health Systems, University of Waterloo (Email: stolee@uwaterloo.ca)

George Heckman, School of Public Health and Health Systems, University of Waterloo (Email: ggheckman@uwaterloo.ca)

Note: Arsalan Afzal is a CCAC staff member and is conducting this study for his PhD dissertation

Purpose: You are invited to participate in an evaluation study for improving the way rehabilitative services are provided to patients though the CCAC's Stroke Community Rehabilitation Program. Because you or your loved one have received services offered through this program, your opinions are important to this study.

Procedures: If you agree to participate in this research, you are invited to complete a survey that will involve questions about your/your loved one's experience of receiving care through the Stroke Community Rehabilitation Program. The survey will take around 20 minutes to complete. The questions are quite general (for example, Did you or your loved one receive enough information from your community stroke team about how they could help you?). Participation in this project is voluntary. Further, all information you provide will be considered confidential. You can skip any question you wish by leaving it blank and withdraw from the study at any time by not returning the questionnaire.

Confidentiality: Confidential data from this questionnaire will be analyzed by the research team. Your name and any identifiable information will be removed from the dataset. No individual participant or names will be recorded, identified or linked to the results. Only the evaluation team will have access to the data, which will be stored on a secured network. Electronic files will be password protected and will be erased using appropriate file deletion software. The data will be retained for five years after the data is collected. The results of this study may be shared through a publication paper, conferences and/or presentations.

Potential risk & benefits: There are no known risks to participating in the survey. If you agree to participate, you will contribute information that may be beneficial to health services planners. Also, you participation will help future stroke patients by improving service delivery, patient experiences, and policies that are relevant to this program.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision about participation is yours. Should you have comments or concerns resulting from your participation in this study, please contact Dr. Maureen Nummelin in the Office of Research Ethics at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

Questions: If you have any questions about this research study, please feel free to contact any of the following:

Arsalan Afzal (Email: Arsalan.afzal@uwaterloo.ca)

Paul Stolee (Email: stolee@uwaterloo.ca)

George Heckman (Email: ggheckman@uwaterloo.ca)

Thank you for your assistance with this project.

Appendix C: Phone Script

Hello, my name is [INSERT NAME] and I am calling from Waterloo Wellington Community Care Access Centre on behalf of a research team from University of Waterloo. May I speak with [PATIENT NAME].

If [PATIENT NAME] is not available:
Do you know when [PATIENT NAME] is expected back? Thank you. I will try and call again.

If [PATIENT NAME] is available:
Good afternoon/evening, my name is [FULL NAME] and I am calling from Waterloo Wellington Community Care Access Centre on behalf of a research team from University of Waterloo. We are looking for participants who can help by providing information on how the Community Care Access Centre improves [Stroke Community Rehabilitation] services and the way they are provided.
Would this be something you would be interested in?

[NO]
Thanks for taking my call.

[YES]

The CCAC is the organization that helps connect people to home care services, such as nursing, personal support assistance or therapy. Your feedback on your experience will be used to help improve the rehabilitation services provided by the Community Care Access Centre and also to show where they are doing well and not so well in providing these services.

The [questionnaire] will take around 20 minutes to complete. The information you provide will help us improve rehabilitation services. The study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. Your responses will be kept confidential, and you will not be identified in any report on this study. You can refuse to answer any questions and to withdraw from the study at any time. Your answers will not change the services you receive.

Would this be something you would be interested in?
[IF YES]
Proceed with Patient Experience Questionnaire

Appendix D Patient Experience Instrument

Patient Experience
Stroke Rehabilitation Team in Home

We want to ask you some questions about the stroke team that provided you rehabilitative care in your home after your hospital discharge. Your feedback is very important as it helps us understand how things are working for our patients' point of view. We use the information to improve our service. Your participation in this questionnaire is confidential and will not change the services you receive. Thank you for helping us to better understand our patient's experience.

Please answer the following questions related to the care you or your family member has received.

Transitional Care/Discharge

1. At the time of my hospital/rehab discharge, I was provided all the information I needed about the stroke community program
   ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

2. I felt confident at the time of my hospital/rehab discharge because I knew I would receive help in home
   ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

3. I knew what my next treatment plan was once I was discharged from the hospital
   ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

4. The community therapist that visited me in my home also met with me in the hospital
   ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

Timely Access to Care

5. My community stroke team's therapist visited me within 48 hours of my hospital/rehab discharge
   ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

6. It was helpful that my community stroke team therapist visited me within 48 hours of my hospital/rehab discharge
   ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

7. I knew I could speak to my community team's therapist or another team member over the phone anytime seven times a week
   ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

Integrated Care (Consolidated services)

8. All health professionals that came to visit me in home knew what my care plan and treatment goals were.
   ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

9. All health professionals that came to visit me in home worked together as one team to help me achieve my goals
   ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

Page 1 of 3

10. I did not have to repeat my information to team members
☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

Information on community resources

11. I received enough information from my community stroke team about how they could help me
☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

12. I received enough information from my team or the care coordinator about other help in the community such as:

☐ Stroke survivors support groups

☐ Day programs

☐ Exercise programs /YMCA

☐ Stroke Recovery Canada

☐ Self-Management Programs

☐ I received no information about the above programs

Returning to Activities
(Select Not Applicable if you never participated in activities in the following questions)

13. I felt confident in managing my own care as a result of my involvement with the stroke team
☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

14. I have returned to participating in sporting activities
☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

15. I have returned to participating in social activities
☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

16. I have returned to participating in house hold roles such as cooking or gardening
☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

Use of Emergency Departments

17. During the time that you received care from the stroke team in your home, did you visit the emergency department?
☐ Yes   ☐ No

18. My reason for the Emergency Department visit was related to my stroke
☐ Yes   ☐ No

19. Working with the team helped me avoid going to the Hospital Emergency Department
    ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

20. Overall, I am satisfied with the help I have received from the community stroke team

    ☐ Very Dissatisfied   ☐ Dissatisfied   ☐ Neutral   ☐ Satisfied   ☐ Very Satisfied

21. I would recommend this team to another family member or friend
    ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

22. I received enough information about recovery and rehabilitation after stroke
    ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

23. I believe the help I have received from this team has met my needs
    ☐ Strongly Disagree   ☐ Disagree   ☐ Neutral   ☐ Agree   ☐ Strongly Agree   ☐ Not Applicable

Strengths: From your experience working with the team, what is the team good at?
Areas for Improvement: From your experience working with the team, what do you think the Team could do better?
Comments: Please provide any other comments.

Please return this survey to:

Attn: Arsalan Afzal
141 Weber Street South, Waterloo ON N2J 2A9

Appendix E Ethics Approvals

Ethics Clearance (ORE # 20856)

ORE Ethics Application System [OHRAC@uwaterloo.ca]
Sent: Thursday, August 06, 2015 4:22 PM
To: Paul Stolee; George Heckman
Cc: Arsalan Afzal

Dear Researcher:

The recommended revisions/additional information requested in the ethics review of your ORE application:

Title: Evaluation of an evidence based Stroke rehabilitation community program
ORE #: 20856
Faculty Supervisor: Paul Stolee (stolee@uwaterloo.ca)
Faculty Supervisor: George Heckman (ggheckman@uwaterloo.ca)
Student Investigator: Arsalan Afzal (a5afzal@uwaterloo.ca)

have been reviewed and are considered acceptable. As a result, your application now has received full ethics clearance.

A signed copy of the Notification of Full Ethics Clearance will be sent to the Principal Investigator or Faculty Supervisor in the case of student research.

****
Note 1: This ethics clearance through a University of Waterloo Research Ethics Committee (REC) is valid for one year from the date shown on the certificate and is renewable annually. Renewal is through completion and ethics clearance of the Annual Progress Report for Continuing Research (ORE Form 105).

Note 2: This project must be conducted according to the application description and revised materials for which ethics clearance has been granted. All subsequent modifications to the project also must receive prior ethics clearance (i.e., Request for Ethics Clearance of a Modification, ORE Form 104) through the Office of Research Ethics and must not begin until notification has been received by the investigators.

Note 3: Researchers must submit a Progress Report on Continuing Human Research Projects (ORE Form 105) annually for all ongoing research projects or on the completion of the project. The Office of Research Ethics sends the ORE Form 105 for a project to the Principal Investigator or Faculty Supervisor for completion. If ethics clearance of an ongoing project is not renewed and consequently expires, the Office of Research Ethics may be obliged to notify Research Finance for their action in accordance with university and funding agency regulations.

Note 4: Any unanticipated event involving a participant that adversely affected the participant(s) must be reported immediately (i.e., within 1 business day of becoming aware of the event) to the ORE using ORE Form 106. Any unanticipated or unintentional change which may impact the research protocol, information-consent document or other study materials must be reported to the ORE within 7 days of the deviation using ORE Form 107.

Best wishes for success with this study.

Julie Joza, MPH
Senior Manager
Office of Research Ethics

Ethics Clearance (ORE # 20857)

ORE Ethics Application System [OHRAC@uwaterloo.ca]
Sent: Tuesday, May 24, 2016 3:29 PM
To: George Heckman; Paul Stolee
Cc: Arsalan Afzal

Dear Researcher:

The recommended revisions/additional information requested in the ethics review of your application for the study:

Title: Patient and Staff Experience - Evaluation of a Stroke Rehabilitation Community Program
ORE #: 20857
Faculty Supervisor: George Heckman (ggheckman@uwaterloo.ca)
Faculty Supervisor: Paul Stolee (stolee@uwaterloo.ca)
Student Investigator: Arsalan Afzal (arsalan.afzal@uwaterloo.ca)

have been reviewed and are considered acceptable. A University of Waterloo Research Ethics Committee is pleased to inform you this study has been given ethics clearance.

A signed copy of the notification of ethics clearance will be sent to the Principal Investigator (or Faculty Supervisor in the case of student research). Ethics approval to start this research is effective as of the date of this email. The above named study is to be conducted in accordance with the submitted application (Form 101/101A) and the most recent approved versions of all supporting materials.

University of Waterloo Research Ethics Committees operate in compliance with the institution's guidelines for research with human participants, the Tri-Council Policy Statement for the Ethical Conduct for Research Involving Humans (TCPS, 2nd edition), Internalization Conference on Harmonization: Good Clinical Practice (ICH-GCP), the Ontario Personal Health Information Protection Act (PHIPA), and the applicable laws and regulations of the province of Ontario. Both Committees are registered with the U.S. Department of Health and Human Services under the Federal Wide Assurance, FWA00021410, and IRB registration number IRB00002419 (Human Research Ethics Committee) and IRB00007409 (Clinical Research Ethics Committee).

****
Renewal: Multi-year research must be renewed at least once every 12 months unless a more frequent review has otherwise been specified by the Research Ethics Committee on the signed notification of ethics clearance. Studies will only be renewed if the renewal report is received and approved before the expiry date (Form 105 - https://uwaterloo.ca/research/office-research-ethics/research-human-participants/renewals). Failure to submit renewal reports by the expiry date will result in the investigators being notified ethics clearance has been suspended and Research Finance being notified the ethics clearance is no longer valid.

Modification: Amendments to this study are to be submitted through a modification request (Form 104 - https://uwaterloo.ca/research/office-research-ethics/research-human-participants/modifications) and may only be implemented once the proposed changes have received ethics clearance.

Adverse event: Events that adversely affect a study participant must be reported as soon as possible, but no later than 24 hours following the event, by contacting the Chief Ethics Officer. Submission of an adverse event form (Form 106 - https://uwaterloo.ca/research/office-research-ethics/research-human-participants/report-problems) is to follow the next business day.

Appendix F Program Logic Model for the Patient Experience Instrument

Input → **Outputs** → **Outcomes**

Input
- Designated Stroke Care Coordinators
- Consolidated Service Provision
- Discharge Link meeting
- First home visit within 48 hours
- Rehab therapy as per best practices
- 24/7 on call access
- Case Conferences involving the patient

Outputs
- Ensuring stroke patients are part of this program
- Ensuring stroke patients have all the information needed
- One Community Stroke Team
- Patient knows about their next provider and treatment plans are
- Timely access to services
- Access to therapy as per best practices
- Patients are linked to other community resources e.g. stroke survivors group

Outcomes
- Functional Independence
- Patient returning to activities
- Improved Transitional Care
- Patients at the centre of their care plan
- Potential avoidance to ED
- Usage of Community Support Services

Stroke Evaluation Survey

Appendix G Multiple Linear Regression Model - ADL Long Form Scale

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.807[a]	.652	.650	4.374

a. Predictors: (Constant), Predicted probability, ADL Long Form 1, Treatment Group

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	21074.193	3	7024.731	367.245	.000[b]
	Residual	11266.488	589	19.128		
	Total	32340.681	592			

a. Dependent Variable: ADL Long Form 2

b. Predictors: (Constant), Predicted probability, ADL Long Form 1, Treatment Group

Coefficients[a]

Model	Unstandardized Coefficients		Standardized Coefficients		
	B	Std. Error	Beta	t	Sig.

1	(Constant)	3.249	.628		5.176	.000
	Treatment Group	-1.057	.450	-.067	-2.349	.019
	ADL Long Form 1	.801	.026	.769	30.529	.000
	Predicted probability	-2.185	.892	-.070	-2.449	.015

a. Dependent Variable: ADL Long Form 2

Appendix H Multinomial Logistic Regression Model - IADL Difficulty Scale

```
NOMREG IADL_Difficulty_cat_2 (BASE=LAST ORDER=ASCENDING) BY Treatment2
IADL_Difficulty_cat_1 WITH
    propensity_score
  /CRITERIA CIN(95) DELTA(0) MXITER(100) MXSTEP(5) CHKSEP(20)
LCONVERGE(0) PCONVERGE(0.000001)
    SINGULAR(0.00000001)
  /MODEL
  /STEPWISE=PIN(.05) POUT(0.1) MINEFFECT(0) RULE(SINGLE)
ENTRYMETHOD(LR) REMOVALMETHOD(LR)
  /INTERCEPT=INCLUDE
  /PRINT=CLASSTABLE FIT PARAMETER SUMMARY LRT CPS STEP MFI.
```

Nominal Regression

Case Processing Summary

		N	Marginal Percentage
IADL Difficulty Follow up	No Difficulty - Minor Difficulty	110	18.5%
	Moderate Difficulty	84	14.2%
	Severe Difficulty	399	67.3%
Treatment Group 2	Treatment Group	404	68.1%
	Control Group	189	31.9%
IADL Difficulty Baseline	No Difficulty - Minor Difficulty	73	12.3%
	Moderate Difficulty	96	16.2%
	Severe Difficulty	424	71.5%
Valid		593	100.0%
Missing		0	
Total		593	
Subpopulation		583[a]	

a. The dependent variable has only one value observed in 581 (99.7%) subpopulations.

Model Fitting Information

Model	Model Fitting Criteria -2 Log Likelihood	Likelihood Ratio Tests Chi-Square	df	Sig.
Intercept Only	1012.394			
Final	660.009	352.385	8	.000

Goodness-of-Fit

	Chi-Square	df	Sig.
Pearson	1130.311	1156	.700
Deviance	657.236	1156	1.000

Pseudo R-Square

Cox and Snell	.448
Nagelkerke	.547
McFadden	.347

Likelihood Ratio Tests

Effect	Model Fitting Criteria -2 Log Likelihood of Reduced Model	Likelihood Ratio Tests Chi-Square	df	Sig.
Intercept	660.009[a]	.000	0	.
Propensity Score	674.739	14.730	2	.001
Treatment Group 2	675.839	15.830	2	.000
IADL Difficulty Baseline	948.599	288.590	4	.000

The chi-square statistic is the difference in -2 log-likelihoods between the final model and a reduced model. The reduced model is formed by omitting an effect from the final model. The null hypothesis is that all parameters of that effect are 0.

a. This reduced model is equivalent to the final model because omitting the effect does not increase the degrees of freedom.

Parameter Estimates

IADL Difficulty Follow up[a]		B	Std. Error	Wald	df	Sig.	Exp(B)	95% Confidence Interval for Exp(B) Lower Bound	Upper Bound
No Difficulty - Minor Difficulty	Intercept	-6.952	.966	51.7769	1	.000			
	Propensity Score	4.487	1.258	12.7720	1	.000	88.8876	7.548	1046.453

		B	Std. Error	Wald	df	Sig.	Exp(B)	Lower Bound	Upper Bound
	[Treatment Group 2=0]	1.343	.391	11.775	1	.001	3.832	1.779	8.253
	[Treatment Group 2=1]	0[b]	.	.	0	.	.	.	.
	[IADL Difficulty Baseline=0]	4.454	.424	110.283	1	.000	85.979	37.443	197.433
	[IADL Difficulty Baseline=1]	3.118	.384	66.112	1	.000	22.606	10.661	47.937
	[IADL Difficulty Baseline=2]	0[b]	.	.	0	.	.	.	.
Moderate Difficulty	Intercept	-4.675	.793	34.764	1	.000			
	Propensity Score	2.338	1.098	4.532	1	.033	10.359	1.204	89.137
	[Treatment Group 2=0]	.902	.346	6.780	1	.009	2.465	1.250	4.860
	[Treatment Group 2=1]	0[b]	.	.	0	.	.	.	.
	[IADL Difficulty Baseline=0]	1.443	.622	5.375	1	.020	4.233	1.250	14.333
	[IADL Difficulty Baseline=1]	3.298	.336	96.183	1	.000	27.060	13.999	52.309
	[IADL Difficulty Baseline=2]	0[b]	.	.	0	.	.	.	.

a. The reference category is: Severe Difficulty.

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b. This parameter is set to zero because it is redundant.

```
NOMREG IADL_Difficulty_cat_2 (BASE=LAST ORDER=ASCENDING) BY Treatment2
IADL_Difficulty_cat_1
  /CRITERIA CIN(95) DELTA(0) MXITER(100) MXSTEP(5) CHKSEP(20)
LCONVERGE(0) PCONVERGE(0.000001)
    SINGULAR(0.00000001)
  /MODEL
  /STEPWISE=PIN(.05) POUT(0.1) MINEFFECT(0) RULE(SINGLE)
ENTRYMETHOD(LR) REMOVALMETHOD(LR)
  /INTERCEPT=INCLUDE
  /PRINT=CLASSTABLE FIT PARAMETER SUMMARY LRT CPS STEP MFI.
```

Nominal Regression

Model Fitting Information

Model	Model Fitting Criteria	Likelihood Ratio Tests		
	-2 Log Likelihood	Chi-Square	df	Sig.
Intercept Only	383.522			
Final	45.867	337.655	6	.000

Goodness-of-Fit

	Chi-Square	df	Sig.
Pearson	3.144	4	.534
Deviance	3.182	4	.528

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Pseudo R-Square

Cox and Snell	.434
Nagelkerke	.530
McFadden	.333

Likelihood Ratio Tests

	Model Fitting Criteria	Likelihood Ratio Tests		
Effect	-2 Log Likelihood of Reduced Model	Chi-Square	df	Sig.
Intercept	45.867[a]	.000	0	.
Treatment Group 2	72.197	26.330	2	.000
IADL Difficulty Baseline	354.460	308.592	4	.000

Parameter Estimates

							95% Confidence Interval for Exp(B)	
IADL Difficulty Follow up[a]	B	Std. Error	Wald	df	Sig.	Exp(B)	Lower Bound	Upper Bound

		B	Std. Error	Wald	df	Sig.	Exp(B)	Lower Bound	Upper Bound
No Difficulty - Minor Difficulty	Intercept	-4.013	.398	101.922	1	.000			
	[Treatment Group 2=0]	1.648	.379	18.889	1	.000	5.195	2.471	10.922
	[Treatment Group 2=1]	0[b]	.	.	0	.	.	.	.
	[IADL Difficulty Baseline=0]	4.519	.417	117.667	1	.000	91.751	40.551	207.599
	[IADL Difficulty Baseline=1]	3.191	.377	71.667	1	.000	24.303	11.611	50.871
	[IADL Difficulty Baseline=2]	0[b]	.	.	0	.	.	.	.
Moderate Difficulty	Intercept	-3.204	.331	93.7600	1	.000			
	[Treatment Group 2=0]	1.080	.337	10.2833	1	.001	2.945	1.522	5.699
	[Treatment Group 2=1]	0[b]	.	.	0	.	.	.	.
	[IADL Difficulty Baseline=0]	1.494	.620	5.795	1	.016	4.453	1.320	15.024
	[IADL Difficulty Baseline=1]	3.345	.334	99.9981	1	.000	28.351	14.718	54.612
	[IADL Difficulty Baseline=2]	0[b]	.	.	0	.	.	.	.

a. The reference category is: Severe Difficulty.

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b. This parameter is set to zero because it is redundant.

Table 7.6. – Multinomial Logistic Regression Analysis of 593 Stroke Survivors for functional outcome (IADL difficulty) by treatment assignment (Community stroke rehabilitation pathway vs. Traditional home care).

Outcome Variable	Predictor Variables	β	SE β	Wald's χ^2	OR	p	95% CI for OR	
							Lower	Upper
IADL (0) – No Difficulty – Minor Difficulty	Constant	-6.95	.966	51.769		.000		
	Propensity Score	4.487	1.258	12.720	88.876	.000	7.548	1046.453
	Baseline IADL (0) – No Difficulty – Minor Difficulty	4.519	.417	117.667	91.751	.000	40.551	207.599
	Baseline IADL (1) – Moderate Difficulty	3.191	.377	71.667	24.303	.000	11.611	50.871
	Baseline IADL (2) – Severe Difficulty	.	.	.	.	.	.	.
	Treatment assignment 0 (Treatment)	1.343	.391	11.775				
	Treatment assignment 1 (Control)	.	.	.	.	.	.	.
IADL (1) – Moderate Difficulty	Constant	-3.204	.331	93.760		.000		
	Propensity Score	2.338	1.098	4.532	10.359	.033	1.204	89.137
	Baseline IADL (0) – No Difficulty – Minor Difficulty	1.443	.622	5.375	4.233	.020		

Baseline IADL (1) – Moderate Difficulty	3.298	.336	96.183	27.060	.000	13.999	52.309
Baseline IADL (2) – Severe Difficulty	.	.	.	.	.	.	.
Treatment assignment 0 (Treatment)	.902	.346	6.780	2.465	.009	1.250	4.860
Treatment assignment 1 (Control)	.	.	.	.	.	.	.

Test	Overall model evaluation			χ^2	*df*	*p*	
	Likelihood ratio test			352.385	8	.000	

Note: The reference category in the 3 months follow up IADL difficulty outcome variable is 2 = IADL Severe Difficulty. The reference category in the treatment assignment variable is 1 = Control.

Appendix I Multinomial Logistic Regression Model - ADL Hierarchy Scale

```
NOMREG ADLcat_hier_hc.2 (BASE=LAST ORDER=ASCENDING) BY ADLcat_hier_hc.1
Treatment2 WITH
    propensity_score
  /CRITERIA CIN(95) DELTA(0) MXITER(100) MXSTEP(5) CHKSEP(20)
LCONVERGE(0) PCONVERGE(0.000001)
    SINGULAR(0.00000001)
  /MODEL
  /STEPWISE=PIN(.05) POUT(0.1) MINEFFECT(0) RULE(SINGLE)
ENTRYMETHOD(LR) REMOVALMETHOD(LR)
  /INTERCEPT=INCLUDE
  /PRINT=FIT PARAMETER SUMMARY LRT CPS STEP MFI.
```

Nominal Regression

Case Processing Summary

		N	Marginal Percentage
ADL Hierarchy Categories Follow Up	0 (Independent)	245	41.3%
	1-2 (Supervision required limited impairment)	189	31.9%
	3+ (Extensive assistance required - total dependennce)	159	26.8%
ADL Hierarchy Categories Baseline	0 (Independent)	197	33.2%
	1-2 (Supervision required limited impairment)	225	37.9%
	3+ (Extensive assistance required - total dependennce)	171	28.8%
Treatment Group 2	Treatment Group	404	68.1%
	Control Group	189	31.9%

Valid	593	100.0%
Missing	0	
Total	593	
Subpopulation	585ª	

a. The dependent variable has only one value observed in 584 (99.8%) subpopulations.

Model Fitting Information

	Model Fitting Criteria	Likelihood Ratio Tests		
Model	-2 Log Likelihood	Chi-Square	df	Sig.
Intercept Only	1282.546			
Final	797.216	485.330	8	.000

Goodness-of-Fit

	Chi-Square	df	Sig.
Pearson	1179.510	1160	.338
Deviance	795.830	1160	1.000

Pseudo R-Square

Cox and Snell	.559
Nagelkerke	.631

McFadden	.378

Likelihood Ratio Tests

	Model Fitting Criteria	Likelihood Ratio Tests		
Effect	-2 Log Likelihood of Reduced Model	Chi-Square	df	Sig.
Intercept	797.216[a]	.000	0	.
Propensity Score	814.916	17.700	2	.000
ADL Hierarchy Categories Baseline	1204.114	406.898	4	.000
Treatment Group 2	808.064	10.848	2	.004

The chi-square statistic is the difference in -2 log-likelihoods between the final model and a reduced model. The reduced model is formed by omitting an effect from the final model. The null hypothesis is that all parameters of that effect are 0.

a. This reduced model is equivalent to the final model because omitting the effect does not increase the degrees of freedom.

Parameter Estimates

							95% Confidence Interval for Exp(B)	
ADL Hierarchy Categories Follow Up[a]	B	Std. Error	Wald	df	Sig.	Exp(B)	Lower Bound	Upper Bound

0 (Independent)	Intercept	-5.823	.887	43.145	1	.000			
	Propensity Score	3.485	1.156	9.084	1	.003	32.636	3.383	314.8
	[ADL Hierarchy Categories Baseline=0]	5.342	.480	123.983	1	.000	208.935	81.590	535.0
	[ADL Hierarchy Categories Baseline=1]	3.949	.443	79.489	1	.000	51.863	21.771	123.5
	[ADL Hierarchy Categories Baseline=3]	0[b]	.	.	0	.	.	.	
	[Treatment Group 2=0]	==1.097==	==.342==	==10.264==	==1==	==.001==	==2.996==	==1.531==	==5.8==
	[Treatment Group 2=1]	0[b]	.	.	0	.	.	.	
1-2 (Supervision required limited impairment)	Intercept	-1.373	.605	5.156	1	.023			
	Propensity Score	-.404	.953	.180	1	.672	.668	.103	4.3
	[ADL Hierarchy Categories Baseline=0]	1.930	.430	20.159	1	.000	6.889	2.967	15.9
	[ADL Hierarchy Categories Baseline=1]	3.337	.315	112.070	1	.000	28.131	15.167	52.1
	[ADL Hierarchy Categories Baseline=3]	0[b]	.	.	0	.	.	.	

		.459	.296	2.39 6	1	.122	1.58 2	.885	2.8
[Treatment Group 2=0]									
[Treatment Group 2=1]	0ᵇ	.	.	0	.	.	.		

a. The reference category is: 3+ (Extensive assistance required - total dependennce).

b. This parameter is set to zero because it is redundant.

Without propensity score variable

Parameter Estimates

ADL Hierarchy Categories Follow Upª		B	Std. Error	Wald	df	Sig.	Exp(B)	95% Confidence Interval for Exp(B)	
								Lower Bound	Upper Bound
0 (Independent)	Intercept	-3.55 6	.42 9	68 .6 32	1	.0 00			

		B	Std. Error	Wald	df	Sig.	Exp(B)	Lower Bound	Upper Bound
	[ADL Hierarchy Categories Baseline=0]	5.386	.474	129.197	1	.000	218.377	86.268	552.797
	[ADL Hierarchy Categories Baseline=1]	3.930	.438	80.612	1	.000	50.918	21.591	120.081
	[ADL Hierarchy Categories Baseline=3]	0[b]	.	.	0	.	.	.	.
	[Treatment Group 2=0]	**1.320**	**.327**	**16.267**	**1**	**.000**	**3.744**	**1.971**	**7.111**
	[Treatment Group 2=1]	0[b]	.	.	0	.	.	.	.
1-2 (Supervision required limited impairment)	Intercept	-1.617	.261	38.533	1	.000			
	[ADL Hierarchy Categories Baseline=0]	1.911	.428	19.974	1	.000	6.761	2.924	15.632
	[ADL Hierarchy Categories Baseline=1]	3.330	.314	112.380	1	.000	27.950	15.100	51.736
	[ADL Hierarchy Categories Baseline=3]	0[b]	.	.	0	.	.	.	.

	β	SE β	Wald's χ²	df	p		Lower	Upper
[Treatment Group 2=0]	.438	.282	2.418	1	.120	1.550	.892	2.693
[Treatment Group 2=1]	0[b]	.	.	0	.	.	.	.

a. The reference category is: 3+ (Extensive assistance required - total dependennce).

b. This parameter is set to zero because it is redundant.

Table 7.5. – Multinomial Logistic Regression Analysis of 593 Stroke Survivors for functional outcome (ADL Hierarchy) by treatment assignment (Community stroke rehabilitation pathway vs. Traditional home care).

Outcome Variable	Predictor Variables	β	SE β	Wald's χ²	OR	p	95% CI for OR	
							Lower	Upper
ADL Hierarchy 0 (Independent)	Constant	-5.823	.887	43.145				
	Propensity Score	3.485	1.156	9.084	32.636	.003	3.383	314.802
	Baseline ADL Hierarchy 0 (Independent)	5.342	.480	123.983	208.935	.000	81.590	535.038
	Baseline ADL Hierarchy 1 (Limited impairment)	3.949	.443	79.489	51.863	.000	21.771	123.550
	Baseline ADL Hierarchy 2 (Extensive assistance required)	.	.	.	.	.	.	.
	Treatment assignment 0 (Treatment)	**1.097**	**.342**	**10.264**	**2.996**	**.001**	**1.531**	**5.861**
	Treatment assignment 1 (Control)	.	.	.	.	.	.	.
ADL Hierarchy 1 (Supervision required/limited impairment)	Constant	-1.373	.605	5.156		.023		
	Propensity Score	-.404	.953	.180	.668	.672	.103	4.322
	Baseline ADL Hierarchy	1.930	.430	20.159	6.889	.000	2.967	15.996

Baseline ADL Hierarchy 1 (Limited impairment)	3.337	.315	112.070	28.131	.000	15.167	52.179
Baseline ADL Hierarchy 2 (Extensive assistance required)	.	.	.	.	.	.	.
Treatment assignment 0 (Treatment)	**.459**	**.296**	**2.396**	**1.582**	**.122**	**.885**	**2.827**
Treatment assignment 1 (Control)	.	.	.	.	.	.	.

		χ^2	df	p
Test	Overall model evaluation			
	Likelihood ratio test	485.33	8	0.000

Note: The reference category in the 3 months follow up ADL hierarchy outcome variable is 2 = Extensive assistance required. The reference category in the treatment assignment variable is 1 = Control.

Appendix J Binary Logistic Regression – Depression Rating Scale

```
LOGISTIC REGRESSION VARIABLES DRS_cat_hc.2
  /METHOD=ENTER Treatment2 DRS_cat_hc.1
  /CONTRAST (Treatment2)=Indicator
  /CONTRAST (DRS_cat_hc.1)=Indicator
  /PRINT=GOODFIT
  /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).
```

Logistic Regression

Case Processing Summary

Unweighted Cases[a]		N	Percent
Selected Cases	Included in Analysis	593	100.0
	Missing Cases	0	.0
	Total	593	100.0
Unselected Cases		0	.0
Total		593	100.0

a. If weight is in effect, see classification table for the total number of cases.

Dependent Variable Encoding

Original Value	Internal Value
<3 (No Symptoms of Depression)	0
3+ (Symtoms of Depression)	1

Categorical Variables Codings

		Frequency	Parameter coding (1)
DRS Category Baseline	<3 (No Symptoms of Depression)	459	1.000
	3+ (Symtoms of Depression)	134	.000
Treatment Group 2	Treatment Group	404	1.000

		Control Group	189	.000

Block 0: Beginning Block

Classification Table[a,b]

			Predicted		
			DRS Category Follow Up		
	Observed		<3 (No Symptoms of Depression)	3+ (Symptoms of Depression)	Percentage Correct
Step 0	DRS Category Follow Up	<3 (No Symptoms of Depression)	487	0	100.0
		3+ (Symptoms of Depression)	106	0	.0
	Overall Percentage				82.1

a. Constant is included in the model.

b. The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 0	Constant	-1.525	.107	202.404	1	.000	.218

Variables not in the Equation

			Score	df	Sig.
Step 0	Variables	Treatment Group 2(1)	.078	1	.780
		DRS Category Baseline(1)	127.423	1	.000
	Overall Statistics		127.971	2	.000

Block 1: Method = Enter

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	109.680	2	.000
	Block	109.680	2	.000
	Model	109.680	2	.000

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	447.142[a]	.169	.277

Hosmer and Lemeshow Test

Step	Chi-square	df	Sig.
1	2.831	2	.243

Contingency Table for Hosmer and Lemeshow Test

		DRS Category Follow Up = <3 (No Symptoms of Depression)		DRS Category Follow Up = 3+ (Symtoms of Depression)		
		Observed	Expected	Observed	Expected	Total
Step 1	1	281	284.232	27	23.768	308
	2	140	136.768	11	14.232	151
	3	52	48.768	44	47.232	96
	4	14	17.232	24	20.768	38

Classification Table[a]

		Predicted		
		DRS Category Follow Up		
		<3 (No Symptoms of Depression)	3+ (Symtoms of Depression)	Percentage Correct
Observed				

Ste p 1	DRS Category Follow Up	<3 (No Symptoms of Depression)	473	14	97.1
		3+ (Symtoms of Depression)	82	24	22.6
	Overall Percentage				83.8

a. The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1[a]	Treatment Group 2(1)	-.219	.259	.712	1	.399	.804
	DRS Category Baseline(1)	-2.449	.243	101.4 01	1	.000	.086
	Constant	.187	.254	.539	1	.463	1.205

a. Variable(s) entered on step 1: Treatment Group 2, DRS Category Baseline.

```
LOGISTIC REGRESSION VARIABLES DRS_cat_hc.2
  /METHOD=ENTER Treatment2 DRS_cat_hc.1 propensity_score
  /CONTRAST (Treatment2)=Indicator
  /CONTRAST (DRS_cat_hc.1)=Indicator
  /PRINT=GOODFIT
  /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).
```

With Propensity Score

Logistic Regression

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Case Processing Summary

Unweighted Cases[a]		N	Percent
Selected Cases	Included in Analysis	593	100.0
	Missing Cases	0	.0
	Total	593	100.0
Unselected Cases		0	.0
Total		593	100.0

a. If weight is in effect, see classification table for the total number of cases.

Dependent Variable Encoding

Original Value	Internal Value
<3 (No Symptoms of Depression)	0
3+ (Symtoms of Depression)	1

Categorical Variables Codings

		Frequency	Parameter coding (1)
DRS Category Baseline	<3 (No Symptoms of Depression)	459	1.000
	3+ (Symtoms of Depression)	134	.000

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Treatment Group 2	Treatment Group	404	1.000
	Control Group	189	.000

Block 0: Beginning Block

Classification Table[a,b]

			Predicted		
			DRS Category Follow Up		
	Observed		<3 (No Symptoms of Depression)	3+ (Symtoms of Depression)	Percentage Correct
Step 0	DRS Category Follow Up	<3 (No Symptoms of Depression)	487	0	100.0
		3+ (Symtoms of Depression)	106	0	.0
	Overall Percentage				82.1

a. Constant is included in the model.

b. The cut value is .500

Variables in the Equation

	B	S.E.	Wald	df	Sig.	Exp(B)

Step 0	Constant	-1.525	.107	202.404	1	.000	.218

Variables not in the Equation

			Score	df	Sig.
Step 0	Variables	Treatment Group 2(1)	.078	1	.780
		DRS Category Baseline(1)	127.423	1	.000
		Propensity Score	.441	1	.507
	Overall Statistics		127.988	3	.000

Block 1: Method = Enter

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	109.706	3	.000
	Block	109.706	3	.000
	Model	109.706	3	.000

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	447.116ª	.169	.277

a. Estimation terminated at iteration number 5 because parameter estimates changed by less than .001.

Hosmer and Lemeshow Test

Step	Chi-square	df	Sig.
1	4.898	8	.768

Contingency Table for Hosmer and Lemeshow Test

		DRS Category Follow Up = <3 (No Symptoms of Depression)		DRS Category Follow Up = 3+ (Symtoms of Depression)		Total
		Observed	Expected	Observed	Expected	
Step 1	1	53	54.546	6	4.454	59
	2	55	54.501	4	4.499	59
	3	53	54.462	6	4.538	59
	4	53	54.420	6	4.580	59
	5	55	54.353	4	4.647	59
	6	57	53.722	2	5.278	59
	7	52	53.443	7	5.557	59
	8	50	48.242	9	10.758	59
	9	31	30.028	28	28.972	59
	10	28	29.282	34	32.718	62

Classification Table[a]

			Predicted		
			DRS Category Follow Up		
			<3 (No Symptoms of Depression)	3+ (Symtoms of Depression)	Percentage Correct
	Observed				
Step 1	DRS Category Follow Up	<3 (No Symptoms of Depression)	467	20	95.9
		3+ (Symtoms of Depression)	81	25	23.6
	Overall Percentage				83.0

a. The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	95% C.I.for EXP(B) Upper
Step 1[a]	Treatment Group 2(1)	-.205	.272	.570	1	.450	.814	.478	1.388
	Propensity Score	-.142	.878	.026	1	.871	.867	.155	4.845
	DRS Category Baseline	2.448	.243	101.092	1	.000	11.562	7.175	18.632

Constant	-2.175	.591	13.537	1	.000	.114		

a. Variable(s) entered on step 1: Treatment Group 2, Propensity Score, DRS Category Baseline.

Table 7.7. – Binary Logistic Regression Analysis of 593 Stroke Survivors for psychosocial outcome (Depression Rating Scale) by treatment assignment (Community stroke rehabilitation pathway vs. Traditional home care).

Outcome Variable	Predictor Variables	β	SE β	Wald's χ^2	OR	p	95% CI for OR	
							Lower	Upper
Depression Rating Scale (0 = No Depression, 1 = Depression)	Constant	-2.175	.591	13.537	.114	.000		
	Propensity Score	-.142	.878	.026	.867	.871	.155	4.845
	Baseline Depression DRS (0) No Depression	2.448	.243	101.092	11.562	.000	7.175	18.632
	Treatment assignment 0 (Treatment)	-.205	.272	.570	.814	450	.478	1.388
Test	Overall model evaluation	χ^2	df	p				
	Hosmer and Lemeshow Test	4.898	8	.768				

Note: The reference category in the 3 months follow up DRS = 1 (>3 Symptoms of Depression). The reference category in the treatment assignment variable is 1 = Control.

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