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The Process of Exercise Participation in the Community for Functional Recovery Post Formal Rehabilitation among Survivors of Stroke: a grounded theory study

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Abstract

The effects of stroke pose a challenge on independence and community participation, which are common goals among survivors of stroke during recovery. Exercises are implemented during rehabilitation services and have a profound effect on functional recovery; however, services are limited, where adherence levels to exercise post discharge are less than ideal. The aim of this research was to understand the process of exercise participation for functional recovery among community living survivors of stroke following discharge from formal rehabilitation. Findings of this constructivist grounded theory study provided insight into the phases leading to exercise commitment – contact with a healthcare provider, desire to improve post stroke life, navigating options, and commitment to exercise. Further, the findings gave rise to key insights, which may foster healthcare providers and community services in promoting continued exercise participation among people living with the effects of stroke.

Keywords

Survivors of stroke, post stroke, recovery, functional recovery, exercise, physical activity, rehabilitation, grounded theory

Co-authorship Statement

This thesis was formulated and written through the assistance, guidance, and support of Dr. Denise Connelly. Dr. Connelly will be a co-author on arising publications. Her patience, dedication, expertise, insights and feedback were important in developing an arising theory and assisted with maintaining motivation throughout the research process. Her support and dedication are extremely appreciated. I would also like to recognize the contributions of my advisory committee in shaping the research project.

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List of Abbreviations

ADLs	Activities of daily living
BBS	Berg Balance Scale
FIM®	Functional Independence Measure®
HCP	Healthcare provider
HEP	Home exercise program
PAD	Physical Activity for People with a Disability
QOL	Quality of Life
TPB	Theory of Planned Behaviour

Chapter 1

1 Introduction

1.1 Background and significance

Stroke is a common disabling health condition worldwide with more people living with the effects of stroke as survival rates improve (Feigin, Norrving, & Mensah, 2017; Heart and Stroke Foundation of Canada, 2017; Katan & Luft 2018). Within this paper, “people living with the effects of stroke” and “survivors of stroke” are used interchangeably to describe people who have experienced a stroke and are recovering from the event. Impairment(s) following stroke manifest differently among individuals, however, stroke is known to impact functional independence, activities of daily living (ADLs), and independent community living and reintegration (Lamola, Fanciullacci, Rossi, & Chisari, 2014; Teasell & Hussein, 2016; Teasell & Hussein, 2018; Wood, Connelly, & Maly, 2010). People living with the effects of stroke commonly acknowledge the stroke incident as the point of demarcation between their *pre-stroke* and *post-stroke* lives (Reed, Harrington, Duggan, & Wood, 2010), indicating that stroke not only affects the physical body of a survivor but also impacts psychosocial aspects of individuals.

Exercise (e.g. walking) has been shown to promote functional recovery to assist with independent physical function as survivors of stroke re-integrate to live independently in the community (Wood et al., 2010). Functional recovery is appreciated as improvement and restoration of function and independence with return to participation in the community, ADLs and activities enjoyed before stroke (Lamola et al., 2014; Teasell & Hussein, 2016). Research on the effects of stroke, and stroke recovery, supports the importance of exercise during and following rehabilitation (Hebert et al., 2016). Specifically, participation in exercise has been shown to improve both cognitive (Marzolini, Oh, McIlroy, & Brooks, 2012; Oberlin et al., 2017) and motor impairment(s) post-stroke needed for functional tasks (e.g. walking, stairs, reaching) throughout the course of functional recovery (Batcho, Stoquart, & Thonnard, 2013; Cabanas-Valdés et al., 2016; Chan et al., 2017; Kim, Cho, Kim, & Lee 2015; Lee et al., 2008; Leroux, 2005; Rose et al., 2017; Zhu et al., 2016). Exercise is considered so important that it is introduced and recommended for various effects of stroke during rehabilitation, with

implementation of support for self-directed exercise at home upon discharge for health maintenance (Hebert et al., 2016).

In spite of research demonstrating that exercise enhances stroke recovery, some survivors of stroke do not maintain exercise participation or meet exercise recommendations, and they often lead sedentary lives (Billinger et al., 2014; Outermans, Pool, van de Port, Bakers, & Wittink, 2016; Simpson, Eng, & Tawashy, 2011). The literature suggests that exercise adherence post-rehabilitation is a problem, and that there are numerous facilitators and barriers to exercise participation among survivors of stroke (Damush, Plue, Bakas, Schmid, & Williams, 2007; Outermans et al., 2016; Nicholson et al., 2014; Signal et al., 2016; Simpson et al., 2011). Facilitators, barriers and exercise interventions are further discussed within the context of behaviour change models, such as the Physical Activity for People with a Disability (PAD) Model (van der Ploeg, van der Beek, van der Woude, & van Mechelen, 2004), and theoretical frameworks, such as the Self Efficacy Theory (Bandura, 1977). General themes about ongoing exercise participation in survivors of stroke are found in the literature (Signal et al., 2016); however, there is a gap in our understanding of those people living with the effects of stroke who do adopt an active lifestyle and do adhere to exercise following discharge from formal healthcare.

Within the general population, several authors describe an ‘intention-behaviour’ gap when explaining the disjoint between knowledge of the importance of exercise and exercise participation (Rhodes & de Bruijn, 2013; Sheeran & Webb, 2016; Sniehotta, Scholz, & Schwarzer, 2005); thus, this is reflected by people living with stroke. The ‘intention-behaviour’ gap is meant to label the dissonance between an individual’s plan to exercise and their actions of exercise behaviour. Intention is suggested as the proximal antecedent to behaviour (Rhodes & de Bruijn, 2013) as seen in behaviour change models, such as the Theory of Planned Behaviour (TPB) (Ajzen, 1985) and the PAD Model (van der Ploeg et al., 2004), however, the presence of intention does not necessarily equate to desired behaviour (Rhodes & de Bruijn, 2013).

Despite the benefits of exercise on functional recovery and the knowledge of behaviour models to guide clinicians as discussed above, exercise adherence in survivors of stroke

is less than ideal (Billinger et al., 2014). Therefore, understanding *how* exercise participation occurs from survivors of stroke themselves, who have continued to exercise following formal rehabilitation, may provide new insights to increase exercise adherence for those living with stroke in the community.

1.2 Statement of Thesis Purpose

There is available literature describing the positive effects of exercise on functional recovery post stroke, as well as the challenge(s) of exercise adherence for maintenance or continued improvement in physical function. Understandings of exercise participation for stroke recovery may further benefit from exploring the perspectives of community living survivors of stroke. More specifically, their perspectives about continued exercise participation post formal rehabilitation to maintain and/or improve functional recovery post stroke. Therefore, the purpose of this thesis was to explore how survivors of stroke living in the community continue to participate in exercise to maintain and/or improve functional recovery post stroke following discharge.

The objectives were to:

- 1) Describe the process of continued exercise participation in the community for the purpose to maintain and/or improve functional recovery among people living with the effects of stroke; and
- 2) Identify key influential factors for healthcare providers and community programs to support continued exercise participation among people living with stroke in the community.

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Chapter 2

2 Literature Review

2.1 Stroke: a brief overview

The first part of this review was completed for the purpose of becoming familiar with stroke and the effects of living with a stroke.

2.1.1 Defining stroke

Since founding the Stroke Registry in 1971, the World Health Organization (WHO) has defined stroke as “rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 h or leading to death, with no apparent cause other than that of vascular origin” (Hatano, 1976, p.541; Sacco et al., 2013, p. 2065). With the continuous advances in stroke knowledge and understanding of the nature, mechanisms and physiology, there was a desire to reformulate this definition (Sacco et al., 2013). The World Stroke Organization (2012) offers a broad description of stroke as “a condition where the blood supply to the brain is disrupted, resulting in oxygen starvation, brain damage and loss of function” (World Stroke Organization, 2012, para. 1). This description does not name the cause of stroke, but rather explains that any disturbance(s) resulting in presentation of stroke symptoms is a result of insufficient delivery of oxygen to the brain for optimal function. This description was employed in the present study for determining participant inclusion and exclusion.

2.1.2 Prevalence

For many years, stroke has been a worldwide health concern and has been recognized as a leading cause of death and long-term disability (Feigin, Norrving, & Mensah, 2017; Katan & Luft, 2018; Kalache & Aboderin 1995). A statement released by the Heart and Stroke Foundation of Canada (2017) reported an 80% survival rate for stroke, with more than 400,000 Canadians living with the effects and disability of stroke. The number of survivors is expected to double within the next 20 years (Heart and Stroke Foundation of Canada, 2017), with only a small proportion experiencing full recovery (Billinger et al., 2014). The expected increase of people living with disability following a stroke will

require more recovery support services for survivors who return to community living (Heart and Stroke Foundation of Canada, 2017).

2.1.3 Effects of living with a stroke

The effects of stroke are various depending on several factors and can present in a number of different ways in physical (e.g.. weakness, spasticity), functional (e.g. gait, balance, dressing, coordination), cognitive (e.g. attention, memory, executive function, thinking and processing), communication (e.g. aphasia), and/or emotional aspects (e.g. frustration) (Teasell & Hussein, 2018). The most common impairments post stroke are hemiparesis (weakness) or hemiplegia (paralysis) contralateral to the stroke lesion (Teasell & Hussein, 2018). Additionally, cognitive impairments affect recovery and long-term outcome including survival, ability, and level of independence to perform functional day-to-day and work activities (Patel, Coshall, Rudd, & Wolfe, 2002; Quaney et al., 2009).

The effects of a stroke can impose long lasting impairments for an individual. A systematic review in 2012 indicated reduced levels of cardiorespiratory fitness in survivors of stroke that may persist up to eight years post stroke (Smith, Saunders, & Mead, 2012). These reduced levels of cardiorespiratory fitness are significant in comparison with healthy individuals of the same sex and age (Smith et al., 2012). Loss of strength in lower extremity major muscle groups was found for ambulatory survivors of stroke compared to age-matched controls (Dorsch, Ada, & Canning, 2016). Furthermore, when comparing ambulation of community dwelling survivors of stroke to age and sex matched controls, it was reported that cardiorespiratory fitness, gait velocity, and leg strength were reduced for people living with the effects of stroke (Dunn, Marsden, Van Vilet, Spratt, & Callister, 2017).

Limitations in physical function are related to quality of life (QOL) in people living with stroke. A study by Clarke, Lawrence, & Black (2000) explored patterns in recovery of QOL during the first year post-stroke. When comparing the findings of this study to a community sample of well elderly, it was apparent that survivors of stroke reported a

lower mean QOL score on the Reintegration to Normal Living Index at both three and 12 months post stroke (Clarke et al., 2000). These findings were reinforced by Em et al., (2015), who reported lower QOL total and sub-scores for people living with the effects of stroke in comparison to the general population. Further, stroke has been shown to have a profound effect on the life course of survivors. Reed, Harrington, Duggan and Wood (2010) explored the needs of survivors of stroke and whether these needs were met through a community stroke scheme. Participants described 'stroke' as a devastating event causing a 'split' in their life that was noted as *prestroke* and *poststroke* (Reed et al., 2010). In reconstructing their lives, it was suggested that survivors of stroke needed a diversity of both internal (e.g., confidence and sense of purpose) and external (e.g., informal support network) resources (Reed et al., 2010). The notion of a split between *prestroke* and *poststroke* was also highlighted in a qualitative study by Dowswell et al. (2000) in which a stroke event represented a discontinuity with a previous way of life for many families. People living with the effects of stroke spoke about not feeling like themselves and felt at a further disadvantage with the deterioration of their social lives; they emphasized the "change in status from 'doers' to receivers, from active to passive" (Dowswell et al., 2000, p. 513). A qualitative study provided insight from survivors of stroke that physical activity after a stroke could address these described disruptions in life, and realign individuals toward their *prestroke* selves (Morris, Oliver, Kroll, Joice, & Williams, 2015). Participants of this study recognized the impact of physical activity in improving their physical selves as well as supporting the restoration and re-establishment of their *prestroke* identity (Morris et al., 2015). Physical activity was noted to support participation in activities valued by people living with the effects of stroke, further enhancing the continuity of restoring *prestroke* sense of self (Morris et al. 2015)

2.2 Stroke Recovery and Rehabilitation

The second part of the literature review focused on a brief understanding of a couple aspects of stroke recovery: trajectory, goals, and stages of recovery in the context of formal rehabilitation and community re-integration. After experiencing a stroke, survivors will begin to recover from the acute event. This part of the review explored the

most common goals shared among survivors of stroke to understand the context of recovery for these people.

2.2.1 Stroke recovery: understanding the terms

Recovery from a stroke is classified into neurological recovery and functional recovery (Teasell & Hussein, 2016). Neurological recovery is appreciated as recovery of neurological impairments, which is largely determined by the location and degree of the stroke (Teasell & Hussein, 2016). Functional recovery is recognized as improvement of independence in mobility and ADLs (Teasell & Hussein, 2016). Functional recovery is not dependent on neurological recovery, where it is suggested to proceed for an unknown timeframe beyond the completion of neurological recovery (Teasell & Hussein, 2016). Although both types of recovery are critical for full recovery post stroke, this paper focuses most predominantly on functional recovery as discussed within neuro-rehabilitation. Lamola, Fanciullacci, Rossi, and Chisari (2014) defined functional recovery as “restoration of function with resumption of the previous activity with characteristics comparable to those pre-stroke” (p.260). Within their definition, functional recovery is recognized as an improvement in several different aspects: motor deficit, motor control, ADLs, and community participation (Lamola et al., 2014). It is further understood that functional recovery is an indicator for long-term improvement in QOL (Clarke et al., 2000; Gbiri & Akinpelu, 2013).

2.2.2 Stroke Recovery Trajectory

Recovery from stroke is individually dependent, however, it is recognized that the first three months of recovery is attributed to peak *neurological* recovery (Teasell & Hussein, 2016). Given the highly influenced but independent nature of functional recovery, the literature suggests improvement of function and continued stroke recovery beyond the initial three months (Teasell & Hussein, 2016). This is a timeframe in which the majority of people are no longer exposed to formal rehabilitation and are re-integrating into the community (Hall et al., 2016; Hebert et al., 2016).

2.2.3 Goals of recovery among survivors of stroke

A commonly reported and shared goal among survivors of stroke is to reconstruct their lives where they return to their roles prior to stroke, as well as resume an independent and active part in their own lives, including functional independence for reintegration and participation in community living inside and outside the house (Dowswell et al., 2000; Hammel, Jones, Gossett, & Morgan, 2006; Kwakkel, Kollen, & Lindeman, 2004). Thus, functional recovery, as described above (Lamola et al., 2014; Teasell & Hussein, 2016) is a common goal for survivors of stroke in order to return and participate in their home life with an optimal level of functional independence (Kwakkel et al., 2004).

2.2.4 Role of rehabilitation and healthcare providers for recovery

Individuals admitted to hospital acute care following a stroke receive an assessment to determine an individualized plan for recovery and discharge, including eligibility for rehabilitation (Hebert et al., 2016). AlphaFIM® Instrument (Functional Independence Measure) is an objective measure used to assess disability and functional status, thereby assisting with decision-making for rehabilitation and discharge (Ontario Stroke Network, 2015). Once medically stable, individuals are triaged for requiring rehabilitation in a range of settings based on the effects of stroke, including “acute and post-acute care, inpatient rehabilitation units, outpatient and ambulatory care clinics, community clinics, programs and recreation centres, early supported discharge services, and outreach teams” (Hebert et al., 2016, p. 460).

Rehabilitation is a critical component of stroke recovery with the main objective focused on assisting survivors of stroke in achieving optimal activity levels and performance (Hebert et al., 2016). Canadian Stroke Best Practice Recommendations (CSBPR) defines stroke rehabilitation as, “a progressive, dynamic, goal-orientated process aimed at enabling a person with impairment to reach their optimal physical, cognitive, emotional, communicative, social and functional activity level” (Hebert et al., 2016, p.460).

Different exercises are implemented and recommended during rehabilitation for various effects of stroke (Hebert et al., 2016). Stroke care is provided in teams of health

care providers (HCPs) who collaborate to coordinate their speciality skills and knowledge for optimal recovery from the effects of stroke including physicians, nurses, physiotherapists, occupational therapists, and speech and language therapists (Hebert et al., 2016; Stroke Unit Trialists' Collaboration, 2013). The benefit of organized inpatient care within a stroke unit is recognized in promoting longevity, independence, and home living in survivors; thus, highlighting the importance of support from a multidisciplinary team of HCPs (Stroke Unit Trialists' Collaboration, 2013).

Within the general population, health education is critical to promote health and prevent disease (Nicholson et al., 2013); thus, it is important for HCPs to adequately educate survivors of stroke about several aspects of a stroke, including the recommendation of health promotion through exercise. A past study employed knowledge brokers to implement exercise guidelines post stroke to support HCPs in their role to advocate exercise uptake by their patients recovering from stroke (Willems, Schröder, van der Weijden, Post, & Visser-Meily, 2016). After the intervention of a knowledge broker, more survivors of stroke acknowledged the encouragement they received to be active in comparison to pre-intervention perceptions of support for exercise (Willems et al., 2016). This acknowledgement suggests that education and encouragement by an HCP may strengthen the therapeutic alliance, which may play a role in improved stroke recovery outcomes. The formation and maintenance of a positive therapeutic alliance between a HCP and survivors of stroke was shown to be beneficial for engagement and motivation (Lawton, Haddock, Conroy, & Sage, 2016). An earlier review exploring the impact of physician-patient communication on health status suggested that emotional health, symptom resolution, as well as functional and physiological status are influenced by effective communication (Stewart, 1995). Additionally, it was suggested that successful health outcomes might be influenced by physician-patient agreement on the problem and resolution (Stewart, 1995). Healthcare providers have been found to play a pivotal role in patient engagement in healthcare and rehabilitation, suggesting that engagement is co-constructed through relationships with HCPs (Bright, Kayes, Worrall, & McPherson, 2015). Furthermore, some HCPs recognized the impact of their behaviour as a social factor positively or negatively affecting motivation (MacLean, Pound, Wolfe, & Rudd,

2002). Several HCPs believed they could increase motivation of patients who had a stroke through building rapport and engaging in conversation with survivors about their lives (MacLean et al., 2002). In learning about their lives and interests, HCPs were able to set rehabilitation goals that were perceived as relevant, which was believed to have a positive effect on motivation (MacLean et al., 2002). It is suggested that the effectiveness of goal setting is increased when goals are established within the context of an individual's life to promote meaning and relevance (Reed et al., 2010).

Unfortunately, despite the benefits appreciated during formal rehabilitation, services provided by the collaboration of HCPs do not continue indefinitely, where continuous treatment is not fostered in the community (Clarke & Forster, 2015; Yi, Han, Lee, & Ha, 2015). Historically, the length of stay in rehabilitation services had varied regionally in Canada (Grant, Goldsmith, & Anton, 2014). Statistics from the years 2014/2015 indicated the average length of inpatient rehabilitation for survivors of stroke was 26 days in Ontario (Hall et al., 2016). Upon discharge, HCPs should introduce resources for self-management to support the gains made during rehabilitation and for long-term recovery (Hebert et al., 2016).

2.2.5 Community Re-integration

Community re-integration is recognized as a complex process, and a crucial element of stroke rehabilitation (Bhogal, Teasell, Foley, & Speechley, 2003; Wood, Connelly, & Maly, 2010). Independent living is highly associated with recovery of motor function, and thus, physical ability (Stinear, 2010). Through the perspectives of people living with the effects of stroke, community re-integration involves a series of steps, where gaining physical function (e.g., walking) is recognized as the initial step (Wood et al., 2010). Furthermore, Olawale, Usman, Oke, and Osundiya (2018) identified predictive factors influencing community re-integration, which appear to be related to functional recovery including: cadence, functional mobility, balance, and community mobility. At this point of the recovery process, responsibility shifts to survivors of stroke to maintain and/or improve function as they take on self-management independently (Bhogal et al., 2003; Gresham et al., 1995).

The impacts of impairments following a stroke impose on the process of community re-integration, leaving survivors of stroke dissatisfied (Murtezani et al., 2009; Pang, Eng, & Miller, 2007; Wood et al., 2010). Early supported discharge was shown to translate motor and functional gains acquired during recovery into greater functioning and satisfaction with community re-integration (Mayo et al., 2000). However, it was previously reported that despite existing impairments, some survivors of stroke begin community re-integration in the absence of post-discharge rehabilitation services, or are expected to recover with little to no intervention (Edwards, Hahn, Baum, & Dromerick, 2006; Kusambiza-Kiingi, Maleka, & Ntsiea, 2017). Researchers have noted an apparent absence of community-based rehabilitation, possibly secondary to the shortage of formal rehabilitation services (Clarke & Forster, 2015; Yi et al., 2015). This may further suggest an increased responsibility for people living with the effects of stroke to take up exercise on their own for continued recovery in community living.

2.3 Exercise for Functional Recovery

The third part of this review aimed to explore stroke recovery beyond formal rehabilitation when individuals are required to assume self-management. Given that functional recovery is often a primary goal for survivors of stroke, and that exercise is introduced during rehabilitation for improved physical function, the impact of exercise participation on functional recovery was reviewed in the literature.

2.3.1 Overview

In this research, the term ‘exercise’ was synonymous with ‘physical activity’, and included ‘therapeutic exercise’ provided within the scope and practice of physiotherapy. Overall, exercise was conceptualized as systematic and planned performance of movement and activities with a specific intent to “remediate or prevent impairments; improve, restore, or enhance physical function; prevent or reduce health-related risk factors; and/or optimize overall health status, fitness or sense of well-being” (Kisner & Colby, 2012, p. 2). Evidence supports the use of aerobic and resistance exercise singularly or in combination with one another in enhancing recovery from stroke

(Marzolini et al., 2018). Aerobic and resistance training have been recognized for their versatility for implementation in community-based exercise programs to benefit survivors of stroke after discharge from rehabilitation (Lee et al., 2008).

Exercise challenges deficits in cognitive and motor function, and is considered crucial for functional recovery after stroke. Cognitive deficits may hinder success of physical rehabilitation limiting recovery to perform activities, and thus, independence within the community (Jokinen et al., 2015; Quaney et al., 2009). The summary from a systematic review reported strength of correlations between motor and cognitive impairment after stroke, where the strength of correlations depended on the outcome instrument (Verstraeten, Mark, & Sitskoorn, 2016). Frequent co-existence of gait, balance, and limb function impairment with deficits in attention and executive functioning were among the most consistent findings (Verstraeten et al., 2016). Additionally, functional independence of people living with the effects of stroke is challenged with advancing age. Research conducted within the elderly population suggests that components of cognition, such as attention (Brown, Shumway-Cook, & Woollacott, 1999) and executive function (e.g. estimation, planning, real-time adjustments) (Hausdorff, Yogev, Springer, Simon, & Giladi, 2005) are necessary for functional tasks of balance and ambulation, respectively, which are motor functions that may be affected by stroke (Brown et al., 1999; Hausdorff et al., 2005; Quaney et al. 2009). In addition to promoting motor and cognitive changes, it is suggested that group exercise training can improve the QOL of people living with the effects of stroke with various disability levels (Murtezani et al., 2009).

2.3.2 Studies exploring enhancement of cognitive components for functional recovery in people living with a stroke

A six-month combined aerobic and resistance training program demonstrated significant improvements in cognition as measured by the Montreal Cognitive Assessment (MoCA) (Marzolini, Oh, McIlroy, & Brooks, 2012). Significant improvements ($p < 0.001$) were seen in the overall MoCA score, as well as within the subdomains of attention/concentration ($p = 0.03$) and visuospatial/executive function ($p = 0.002$)

(Marzolini et al., 2012). Additionally, there was a significant reduction ($p < 0.001$) from baseline to post intervention in the number of individuals who met threshold criterion for mild cognitive impairment (Marzolini et al., 2012).

A meta-analysis of 14 randomized controlled trials demonstrated a significant positive overall effect of physical activity (including aerobic exercise, resistance training, or physiotherapy) on cognitive function (including sub group analysis domains of attention and processing speed) post stroke with small to moderate effects in chronic stroke (Oberlin et al., 2017). Cognitive gains were most apparent in individuals who underwent combined aerobic and strength training, thereby emphasizing the influence of exercise on cognition post stroke (Oberlin et al., 2017).

2.3.3 Studies exploring improvement of functional tasks

Studies have demonstrated the impacts of exercise on functional activities measured through objective functional tests. Leroux (2005) performed a study to explore the feasibility and efficacy of a community organization offering an exercise program to people with chronic stroke (≥ 6 months post stroke) with the intent of influencing motor performance. The results demonstrated significant improvement on several functional tests after eight weeks of supervised exercise, including Berg Balance Scale (BBS), 15-second Step Test, and Timed Up & Go test scores ($p < 0.008$). In another study, after four weeks of either land based exercise (e.g. strengthening, trunk mobility, and treadmill training) or hydrotherapy exercise (e.g. strengthening, balance/coordination, and aquatic treadmill training), survivors of stroke demonstrated significant improvement ($p < 0.05$) in several functional outcome measure test scores, including BBS, Functional Reach Test, 2-Minute Walk Test, and Timed Up & Go Test (Zhu et al., 2016). A significantly higher mean improvement ($p < 0.01$) was recognized in the aquatic group on the Functional Reach Test and the 2-Minute Walk Test in comparison to the land based exercise group (Zhu et al., 2016). Improvements on functional test scores reflect improvement in fundamental activities for independent living including walking, stairs, balance, and reaching.

Walking ability is influenced by exercise as described in the following studies. Exercise in the form of task specific locomotor training or strength and balance training provided by a physical therapist have significantly improved walking speed and walking distance in survivors of stroke following an initial 12 sessions of training (Rose et al., 2017). Although results are not generalized, Batcho, Stoquart, and Thonnard (2013) found aerobic activity in the form of regular brisk walking to promote functional recovery while improving walking endurance, as well as stroke-impaired balance and ADLs. A study by Lee et al. (2008) completed with the purpose of determining if walking ability would improve following changes in strength or cardiorespiratory fitness secondary to an exercise intervention, demonstrated that an intervention of progressive resistance training improved muscle strength, power and endurance with a significant improvement in stair climbing power by 17% ($p=0.009$). Additionally, self-efficacy for ascending stairs and tasks requiring walking were also improved (Lee et al. 2008). These findings for stair climbing ability and self-efficacy are important as motor function required for ascending and descending stairs is transferrable and necessary for community living; not only will survivors of stroke have to manage stairs, but also curbs and ramps within the community (Lee et al., 2008). Within this study, an aerobic exercise intervention was shown to improve only indicators of cardiorespiratory fitness. Neither aerobic nor strength training were shown to significantly improve walking distance or gait velocity; however, the combination of the two provided greater effects on mobility and impairment outcomes in comparison to either single modality (Lee et al., 2008). Another study found that an exercise intervention in the form of stationary cycling increased both balance and gait abilities in people living with chronic effects of stroke over a six week intervention (Kim, Cho, Kim, & Lee, 2015). In this study, both the experimental and control group engaged in a conventional rehabilitation program; additionally, the experimental group completed 30 minutes of stationary cycling exercise five times per week (Kim et al., 2015).

When exploring exercise perceptions among survivors of stroke, balance has been identified as important for community participation and exercising (Simpson, Eng, & Tawashy, 2011). A study by Cabanas-Valdés et al. (2016) sought to explore the effects of core stability exercises in addition to conventional therapy during the subacute phase of

stroke recovery. Within the experimental group, core stability exercises were performed for 15 minutes a day and consisted of tasks involving repetitive movement to improve core strength, endurance and coordination. After five weeks, core stability exercises were shown to improve components of balance (trunk control, and dynamic sitting and standing balance), as well as gait, and ADLs. In another study, Chan et al. (2017) explored the effects of water-based exercises on balance in subacute stroke, where participants completed an intervention of water and land training (water group) or land training (land group) only. The results of the water group demonstrated improvements in mean BBS and Community Balance and Mobility Test with change scores (6 ± 3 and 10 ± 5 , respectively) greater than the minimal detectable change (6 points and 7.5 points, respectively) (Chan et al., 2017; Stevenson 2001). The 2-Minute Walk Test improved greater than the minimal detectable change (MDC 13m) in both groups (water group = 20 ± 14 , land group 17 ± 18), thus recognizing the benefits of land exercise in the absence of water based exercise (Chan et al., 2001; Hiengkaew, Jitaree, & Chaiyawat, 2012).

Reaching ability was assessed by Thielman, Dean, and Gentile (2004) where survivors of stroke were randomly assigned to one of two groups post discharge from rehabilitation services: task-related training or progressive resistive exercise. The objective was to evaluate the effectiveness of the training programs on improving reaching ability of their paretic limb. Results suggested that improvements were dependent on initial level of functioning. Individuals who portrayed a lower level of impairment showed decreased compensatory use of trunk when reaching to the ipsilateral target after an intervention of progressive resistive exercise.

In addition to functional gains, familiarity with and exposure to exercise appears to reinforce exercise participation (Sharma, Bulley, & van Wijck 2012). This is important for community living survivors of stroke for continued functional benefits received through exercise. Referral to an exercise program has been shown to stimulate physical activity levels both within and outside exercise sessions, again reinforcing independent exercise participation (Sharma et al., 2012). With implementation of referral to exercise,

survivors of stroke reported improvement in fitness, strength, movement and mood (Sharma et al., 2012).

2.3.4 Reasons to continue exercising beyond formal rehabilitation

As described above, functional recovery post stroke is positively promoted through exercise. Given the notion that exercise improves function, exercise is then critical to gain physical function to support the process of community re-integration, as well as to achieve general goals of functional independence and active participation in the community and life (Hammel et al., 2006; Kwakkel et al., 2004; Wood et al., 2010). Studies have demonstrated the importance of addressing exercise behaviour as a continuous intervention for recovery in community living survivors of stroke (Batcho et al., 2013; Rose et al., 2017). Recently, Rose et al. (2017) found that survivors of stroke did not experience a recovery plateau at six months, but rather were responsive to an exercise stimulus when exposed to an exercise intervention. Previously, Batcho et al. (2013) reported significant improvement of functional recovery in people living with chronic effects of stroke during an intervention of brisk walking. There were no significant changes in functional recovery in the absence of intervention (pre and post), indicating the importance of an ongoing exercise stimulus for continued recovery (Batcho et al., 2013).

2.4 Exercise Behaviour Post Stroke

Given that exercise helps to achieve the goals of functional mobility and increased independence for survivors of stroke, the last part of the literature review aims to explore the current understanding of exercise behaviour among survivors of stroke.

2.4.1 Adherence

For the majority of survivors of stroke, mobility gains at the time of discharge from rehabilitation are incomplete (Paolucci et al., 2001). As a result, and in addition to limited rehabilitation services, exercise participation and general mobility may be limited in comparison to the lifestyle of healthy counterparts (Yi et al., 2015), or mobility levels

prior to stroke. Post discharge rehabilitation treatment has been shown to prevent deterioration in mobility and increase the likelihood of mobility improvement (Paolucci et al., 2001), thus indicating the importance of adhering to exercise.

A home exercise program (HEP) provided at discharge requires high adherence to the exercise program and motivation on behalf of survivors of stroke to achieve continued benefits, however, reported adherence rates to the HEP are less than ideal (Miller, Porter, DeBraun-Sprague, Van Puymbreck, & Schmid, 2017). Miller and colleagues (2017) distributed a survey to survivors of stroke to explore their adherence rates to a post rehabilitation HEP designed for continued improvement through exercise. Of the participants in the study, 89% reported receiving a HEP, where 65.3% reported being adherent with only part of the HEP rather than the entire program (Miller et al., 2017). Despite the benefits of exercise, survivors of stroke generally do not meet the recommendations of physical activity required for a healthy lifestyle, and often lead sedentary lives (Billinger et al., 2014; Outermans, Pool, van de Port, Bakers, & Whittink, 2016; Simpson et al., 2011). The physical activity and exercise recommendations for survivors of stroke include an aerobic (3-5 days/wk), muscular strength/endurance (2-3 days/wk), flexibility (2-3 days/wk), and neuromuscular component such as balance and coordination activities (2-3 days/wk) (Billinger et al., 2014). Exercise recommendations are used as a reference for designing community based exercise guidelines and determining which components should be incorporated into community classes (Ontario Stroke Network, 2015). A systematic review completed to describe physical activity levels across the stages of stroke recovery (acute, sub-acute, and chronic) reported that time spent in a sedentary state was >78% regardless of the time post stroke (Fini, Holland, Keating, Simek & Bernhardt, 2017). With that being said, people living with the effects of stroke risk losing functional gains accomplished during rehabilitation (Shaughnessy, Resnick, & Macko 2006). Fewer survivors of stroke living in the United States met weekly physical activity recommendations when compared to adults without stroke (17.9% vs. 25% respectively) (Butler & Evenson, 2014).

Poor adherence rates in the community might possibly be attributed to exercise programs and community facilities. Insights from community dwelling survivors of stroke suggest that community programs have difficulty meeting the needs of people living with the effects of stroke (Simpson et al., 2011). Exercise support from leaders who understand the challenges and capabilities of people living with stroke was considered an essential feature to a program (Simpson et al., 2011). Adherence may also be better understood in terms of exercise group dynamics. An overview exploring the literature of cohesion in exercise groups suggested that exercising with others as part of a group is associated with higher adherence (Burke, Carron, & Shapcott, 2008). Intentions held by individuals to be physically active are influenced by exercise groups (Burke et al., 2008). Furthermore, stronger beliefs/perceptions held by individuals about the cohesiveness of their exercise class positively influences adherence levels (Burke et al., 2008; Estabrooks, 2000).

Survivors of stroke have reported the challenge of maintaining the motivation to continue exercising, and thus, adhering and committing to exercise (Poltawski et al., 2015). Further, there appears to be a synergy or dissonance between motivation and capability, depending on survivors' beliefs, attitudes, physical context, and social context (Morris, Oliver, Kroll, Joice, & William, 2017). In motivated survivors of stroke, dissonance occurred in the presence of limited capability (i.e. resources to be active) for physical activity, thus, demonstrating an impact on adherence rate (Morris et al., 2017).

2.4.2 Facilitators and barriers to exercise

Adherence rates may be better understood when exploring components influencing behaviour. Nicholson et al. (2014) stated the importance of understanding perceived facilitators and barriers to become active in order to best support people living with the effects of stroke. A variance in exercise behaviour exists, and there is a direct influence by HCPs in telling an individual to exercise (Shaughnessy et al., 2006). Past literature has explored facilitating and debilitating factors to exercise in survivors of stroke, including individuals living in the community. Common facilitators to exercise include, but are not limited to, social support and interaction (Damush, Plue, Bakas, Schmid, & Williams, 2007; Nicholson et al., 2014; Signal et al., 2016; Simpson et al., 2011), beliefs about the

benefits of exercise (Nicholson et al. 2014), high self-efficacy (Nicholson et al., 2014, Outermans et al., 2016), high motivation (Damush et al., 2007), positive attitude (Outermans et al., 2016) and necessity of routine behaviours (Nicholson et al., 2014). Some barriers to exercise include physical impairments (Damush et al., 2007; Outermans et al., 2016), lack of motivation (Damush et al., 2007), low self-efficacy (Outermans et al., 2016; Simpson et al., 2011), negative attitude (Outermans et al., 2016), environmental factors (Damush et al., 2007; Outermans et al., 2016), and lack of professional support upon discharge from formal care (Nicholson et al., 2014). As seen in a study by Outermans and colleagues (2016), several personal and environmental factors have both facilitating components as well as barriers imbedded within them (e.g. self efficacy, attitude).

2.4.3 Exploring themes of continued exercise

Signal et al. (2016) completed a qualitative descriptive study nested in a mixed methods pilot randomized controlled trial (RCT). As part of the RCT, survivors of stroke participated in group based exercise rehabilitation at an intensity of moderate to high over the course of 12 weeks. Participants then underwent interviews post intervention with a focus on acceptability of the exercise intervention, barriers and facilitators to exercise engagement, as well as the experiences of high intensity exercise. As part of the interview, six major themes arose surrounding acceptability of, and ongoing engagement in exercise: making progress, sourcing motivation, working hard, the people, 'fit with me', and 'fit with life'. The notion of 'making progress' was described in terms of experiencing success through marked improvements in exercise ability, identifying gains in impairment and confidence, and identifying future possibilities. 'Sourcing motivation' was represented through internal and external factors and is closely linked to 'the people'. The high intensity exercises were reported to force individuals to focus and work hard, which was linked to their sense of success. Lastly, survivors of stroke expressed the suitability of the exercise intervention for themselves and within their lives. This study gave rise to general themes surrounding continued exercise participation within the stroke population.

2.4.4 Behaviour change

In order to promote behaviour change to improve long-term activity participation and functional exercise capacity post stroke, it has been proposed that interventions should “incorporate PA-specific tailored counselling based on sound behavioural theory” (Morris, MacGillivray, & Mcfarlane, 2014, p.965).

Several theoretical frameworks and behaviour change models exist in an attempt to describe, understand and promote a specified behaviour, including, but not limited to Self-efficacy Theory (Bandura, 1977), TPB (Ajzen, 1985), and PAD Model (van der Ploeg, van der Beek, van der Woude, & van Mechelen, 2004). Using the Self-Efficacy theory framework, the influence of an educational and motivational program with sequential follow up on exercise behaviour post stroke was explored by Shaughnessy and Resnick (2009). Shaughnessy and Resnick (2009) implemented an exercise intervention developed for subacute survivors to promote exercise education and motivation over 12 weeks. The intervention was known as ‘Reshaping Exercise Habits and Beliefs’ (REHAB). REHAB begins with a one-hour educational session about stroke and exercise with exercise prescriptions tailored to the individual. Each individual received weekly structured phone calls, which contained a theoretically driven motivation component with inherent self-efficacy enhancement tactics. Despite the labour intensive and participant specific challenges of the intervention, REHAB, underpinned by a theoretical framework, demonstrated success in improving activity, exercise, and social participation.

As discussed above, survivors of stroke have low adherence rates even in the presence of and guidance from behaviour change models for specific intervention. Alongside barriers and facilitators to exercise, ‘intention’ is considered a proximal antecedent to behaviour (Rhodes & de Bruijn, 2013), as reflected in behaviour change models such as TPB (Ajzen, 1985) and PAD Model (van der Ploeg et al., 2004). Unfortunately, there is a notable ‘intention-behaviour’ gap in the literature amongst several populations (Rhodes & de Bruijn, 2013; Sheeran & Webb, 2016; Sniehotta, Scholz, & Schwarzer, 2005). The PAD model suggests some environmental (e.g. social influence, transportation) and personal factors (e.g. self efficacy, attitude, health condition) that may influence this

'gap' (van der Ploeg et al., 2004). Other studies have been completed to further explore the gap and to mediate the relationship between intention and behaviour (Godin, Conner, & Anton, 2005; Rhodes & de Bruijn, 2013; Sheeran & Webb, 2016; Sniehotta et al., 2005). It becomes critical to understand the process that community exercising survivors of stroke undertake for continued exercise participation in order to bridge the notable gap. The PAD model was utilized by Outermans et al. (2016) to explore perceived barriers and facilitators to outdoor walking amongst survivors of stroke, which were partly identified above. The results of the study were mapped onto the model for a comprehensive overview. This study proposed the importance of influencing intention to become active (e.g. outdoor walking) by addressing personal factors (e.g. self efficacy, attitude) (Outermans et al., 2016). In this study, the PAD Model showed major influences on 'intention' for outdoor walking (Outermans et al., 2016)

2.5 Summary

An overview of findings from this literature review revealed the importance of understanding the process of exercise participation in people living with the effects of stroke in the community. The effects of stroke have a detrimental impact on the lives of people living with stroke (Teasell & Hussein, 2018), where impaired function impacts their goals of living independently, participating in activities, and being an active part of the community. The goals of people living with the effects of stroke are related to functional recovery (Hammel et al., 2006; Kwakkel et al., 2004), where exercise is recognized as a means for improving and maintaining functional recovery. During community re-integration, survivors of stroke take on the role to self-manage continued functional recovery after introduction to exercise during rehabilitation (Bhugal et al., 2003; Gresham et al., 1995). Behaviour change models (Ajzen, 1985; van der Ploeg et al., 2004) and theoretical frameworks (Bandura, 1977) have been used to contextualize positive factors supporting adherence to behaviour changes, such as exercise participation; however, exercise participation is less than ideal with an increased sedentary lifestyle in people living with the effects of stroke (Billinger et al., 2014; Outermans et al., 2016; Simpson et al., 2011). There remains a void in understanding the process of exercise participation for continued functional recovery by people living with

the effects of stroke in the community. Further understanding of the process of exercise participation during the continuum of recovery may lead to better outcomes for people living with the effects of stroke in the community, and enable ideas for HCPs and community services to support continued recovery of this group of people.

2.6 References

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Chapter 3

3 Methodology

This study utilized a constructivist grounded theory approach to explore the process that people living with the effects of stroke engage in as a continuation of exercise in the community for functional recovery.

3.1 Paradigmatic Position

The paradigmatic position in which a researcher resonates is an important aspect to the ongoing process and dissemination of qualitative research (Carpenter & Suto, 2008; Denzin & Lincoln, 2000). Paradigmatic positions are recognized as worldviews and are described by researchers as their way of seeing and acting in the world, thereby acknowledging how it shapes their research (Denzin & Lincoln, 2000; Guba & Lincoln, 1994; Ponterotto, 2005). This way of seeing influences preconceived ideas held by a researcher, as well as the research design they choose to address their question (Guba & Lincoln, 1994; Ponterotto, 2005). In this way of qualitative inquiry, the “researcher is an inextricable part of the research endeavour” (Mantzoukas, 2004, p.1000). Qualitative researchers should be mindful to recognize and understand their paradigmatic position and its influence on the research process, in order to maintain congruency between the most appropriately chosen framework and the research question/purpose (Carpenter & Suto, 2008). The paradigmatic position in which I resonate is described below in ‘statement of reflexivity’.

3.2 Statement of Reflexivity

Within this research, I resonate myself as a constructivist grounded theorist who plays an integral part of the research, where I must acknowledge the impact of both initial and arising preconceptions on the research process (Charmaz, 2006; Tufford & Newman, 2012). ‘Bracketing’ (i.e. being aware) occurred as an iterative process of identifying assumptions arising throughout the research (Charmaz, 2006; Tufford & Newman, 2012). Initial preconceptions arising from personal experiences are offered in the statement of reflexivity, where subsequent memos acknowledged arising ideas through data analysis

and theoretical sampling (Charmaz, 2006; Tufford & Newman, 2012). I hereby offer a statement of reflexivity to acknowledge my position in the research process and to orient readers to my paradigmatic view, background, experiences, beliefs and assumptions that may have impacted the commencement and dissemination of this research.

I acknowledge myself as a co-constructor of meaning through data interpretation as represented in the findings of this study (Morrow, 2005). I hold a constructivist paradigmatic view, as described by Guba and Lincoln (1994). Ontologically, this paradigm adopts a relativist stance and I believe that multiple realities exist rather than one single true reality (Guba & Lincoln, 1994). In my approach to this research I adopted a subjectivist epistemology, where meaning of the phenomena is co-constructed through interaction between the researcher and the participant to uncover meaning (Guba & Lincoln, 1994; Mills, Bonner, & Francis, 2006; Ponterotto, 2005). I strongly believe that each individual lives their own reality, where we all act and feel in different ways based upon our perceptions. I appreciate the uniqueness of each individual, and therefore, deny the notion of a single true reality that can be applied to everyone. Rather, I believe there are similarities that can be presented for consideration by others, which is how I aim to share the understandings co-constructed with the participants in my research. I have always believed that better understanding of phenomenon is achieved through conversation, and that the realizations and meanings are a reflection of the people involved within the conversation. I thereby acknowledge that my writings of the findings are an interpretation of the conversational interactions with my participants, which influenced my understandings of their stories, and so, the findings presented are a co-construction of their stories and my representation of our shared interactions in this research. In resonating with 'constructivist', I recognize that preconceived ideas held by grounded theorists may influence their work if they are unaware of their starting assumptions (Charmaz, 2006). Thus, throughout the research process, I remained reflexive of my personal interpretations and any preconceived notions that existed within myself in an attempt to avoid imposition of such ideas. Additionally, a more substantive literature review was delayed until completion of analysis to avoid and reduce the imposition of preconceived ideas on the unraveling work (Charmaz, 2006).

In addition to the worldview adopted by myself, I provide a brief description of my educational background and work experiences. I have completed a Bachelors of Human Kinetics – Movement Science (BHK) and a Master of Physical Therapy (MPT) degree. Throughout my undergraduate and graduate education, I was exposed to the human body, illnesses and diseases, exercise, as well as behaviour change models. The knowledge attained shaped my beliefs that behaviour is modifiable where a desired outcome can be achieved for the health benefits of an individual, and sometimes through the help of others (e.g. social support). I am aware of some facilitating and debilitating factors contributing to behaviour change, however, this research utilized open-ended interview questions during data collection to prevent the imposition of previous presumptions of specific facilitating and debilitating factors. Additionally, I have experience working as a wellness coach at the YMCA where I assisted individuals in achieving health goals predominantly through the use of exercise. Several success stories enhanced my beliefs that behaviour change is beneficial for the health of an individual.

In learning about and interacting with individuals living with a chronic illness, I believe that the effects of an illness or acquired impairments alter the act of engaging in exercise, where exercise may require more planning and support. As such, exercise to survivors of stroke may be “going for a walk”. I believe exercise programs available may not be specific enough or challenging enough to cause a change. Further, it is believed that exercise does not have to occur at a community centre and can be structured at home.

Through enrolment to the physical therapy program, I was exposed to clinical placements where I gained experience in different settings pertaining to individuals who have experienced a stroke: acute care neurology/neurosurgery and inpatient rehabilitation. These placements showed me the importance of adequately assessing the functional abilities of patients who have had a stroke in order to determine the most appropriate plan moving forward. I also recognized the benefit of intensive rehabilitation in promoting functional ability as I watched someone walk again for the first time. Upon discharge from inpatient rehabilitation, I often wondered if and how individuals would continue to improve functional capacity in the absence of strict and intensive rehabilitation. I was

concerned for their wellbeing in the community and became keen to explore functional improvement while living in the community.

I currently work as a physiotherapist in an orthopaedic clinic where appropriate exercise prescription plays an important role in my treatment plans. Within this setting, I acknowledge that specified exercise is essential to correct imbalances and dysfunctions as a means to reduce pain and improve function. I have suggested, implemented, and instructed a gradual exercise program unique to each individual's needs. I have experienced a positive outcome from incorporation of such treatment, as individuals returned to their desired activities and achieved personal goals. All my experiences, in addition to literature, make me believe that exercise is important for the functional well being of people living with the effects of stroke.

3.3 Grounded Theory

“...you start with individual cases, incidents or experiences and develop progressively more abstract conceptual categories to synthesize, to explain and to understand your data and to identify patterned relationships within it”

(Charmaz, 1996, p.28)

Grounded theory is a qualitative methodology founded by Barney Glaser and Anselm Strauss (1967), which has evolved through different approaches and positions since its establishment (Glaser and Strauss, 1967; Strauss and Corbin 1990; Charmaz 2000). Regardless of the approach pursued, Creswell (2012) identified six key characteristics of a grounded theory study: process approach, theoretical sampling, constant comparative, core category, theory generation, and memo. These characteristics will be discussed later in reference to how they appeared within this research study. Grounded theory inquiry is an emergent process and is inductive in nature, where theory arises from specified data (Charmaz, 1996; Charmaz, 2003).

3.3.1 Constructivist Grounded Theory

A student of Glaser and Strauss, Kathy Charmaz (2000), evolved the grounded theory methodology into a different approach widely recognized as constructivist grounded theory. This approach to grounded theory recognizes that the researcher ('viewer') creates data through interaction with the participant ('viewed') (Charmaz, 2003). Throughout this interactive process, it is acknowledged that the data is reliant on the temporal, cultural, and structural contexts in which the interaction took place and that both the viewer and viewed confer meaning upon the interaction (Charmaz, 2003). Therefore, "the viewer then is part of what is viewed rather than separate from it" (Charmaz, 2003, p. 273). The constructivist underpinning enables participants to relay their story in their terms, where the researcher maintains complete openness to experience (Charmaz, 2003).

3.3.2 Implications of Grounded Theory

Grounded theory is an appropriate methodology to utilize when the purpose of inquiry is "to develop or modify a theory, explain a process, and develop a general abstraction of the interaction and action of people" (Creswell, 2012, p.440). As this study aimed to explore and generate a conceptual understanding regarding the process of exercise participation in people living in the community with the effects of stroke, grounded theory was deemed an appropriate fit.

3.4 Study design

This study utilized a constructivist grounded theory approach informed by Charmaz (2000) to investigate and understand the process of exercise participation outside of structured rehabilitation among survivors of stroke living in the community. Consistent with the relativist and subjectivist stances of 'constructivism' employed in constructivist grounded theory, this study remained open to multiple insights, where meaning was constructed between the researcher and participants (Guba & Lincoln, 1994). Through the subjectivist nature, all the findings were created, rather than imposed, as the study proceeded (Guba & Lincoln, 1994).

Consistent with constructivist grounded theory, this study examined *how* individuals make meaning of exercise and *how* they continue to exercise within the community and outside of structured rehabilitation (Charmaz, 2006). From a constructivist viewpoint, the aim was to move towards a general consensus through understanding and reconstructing meaning that individuals initially hold (Guba & Lincoln, 1994). The resulting consensus of meaning was proposed as a theory dependent on the researcher's interpretation, as the researcher cannot claim to exactly replicate the participants view (Charmaz, 2006).

3.4.1 Participants and recruitment

The target number for participant recruitment for this study was ten people living in the community with the effects of stroke post formal rehabilitation care. Participants were recruited from community centres in Southwestern Ontario that offered stroke-specific exercise classes or exercise space. Ten participants was the target population as qualitative research is more concerned with sampling procedures (e.g., quality and length of in-depth descriptions from participants) rather than sample size (e.g., quantity of participants (Morrow, 2005). Potential volunteers were informed of the study through posters (Appendix A) about the study on community centre bulletin boards, and word of mouth from participants. Potential volunteers were included in the study if they had survived a stroke, were not currently receiving formalized rehabilitation, intended to exercise to maintain and/or improve functional capacity, and were engaged in exercise in the community outside of a structured rehabilitation exercise program at a moderate intensity (e.g. to cause sweating and increased breathing rate). Exercise required planned movement and activities for a purpose of improving or maintaining physical function (Kisner & Colby, 2012). Volunteers were screened for the exclusion criteria and were excluded from the study if they reported either criteria: dysarthria (difficulty speaking) as an effect of stroke, and unable to understand or speak English.

These inclusion and exclusion criteria were used to yield a sample of participants who were believed to be accountable for their own functional recovery by participating in exercise when they were no longer a part of formal rehabilitation. No time limit since the stroke incident or participation in formal rehabilitation was imposed for participation in

the present study to allow the possibility to explore exercise over the continuum of recovery. The inclusion criteria permitted the opportunity to understand the process inherent to individuals to exercise post stroke for the purpose of facilitating functional recovery. Participant recruitment occurred over six months from September 2017 – March 2018. In the event that poor weather might be an influential factor on the ability to participate in exercise, recruitment response and data collection across two seasons of the year, i.e., good weather in Fall and poorer weather in Winter, was strategic to reduce potential limitations of weather on data collection.

3.4.2 Theoretical sampling

A key characteristic of grounded theory – *theoretical sampling* – was employed, where collection, coding and analysis of data occurred simultaneously (Charmaz, 2003; Creswell, 2012; Glaser & Strauss, 1967; Chong & Yeo, 2015). In reference to Charmaz (2006):

“the purpose of theoretical sampling is to obtain data to help you explicate your categories [...] In short, theoretical sampling pertains only to conceptual and theoretical development; it is *not* about representing a population or increasing the statistical generalizability of your results” (p.100 – 101).

Theoretical sampling does not aim to increase the original sample size, but rather, aims to refine ideas and shed light on the emerging theory (Charmaz, 2003). This type of sampling can be utilized earlier or later on in the research, where it is suggested to begin theoretical sampling when there is a need to develop preliminary categories (Charmaz, 2006). As the study proceeded, key ideas were gathered and theoretical sampling was implemented to collect data from participants who had experiences that were anticipated to assist in refining categories and add thick (i.e. in-depth and abundant), rich descriptions to delimited data identified in developing theoretical constructs (Charmaz, 2003; Charmaz, 2006). An iterative process of data analysis and collection informed the interview script and ‘probes’ used to deepen the understandings from participants’ stories collected in subsequent interviews. Theoretical sampling facilitates saturation, where no further or new insights pertaining to a category are revealed by study participants through further data collection (Charmaz, 2006).

3.4.3 Data collection

Participants were invited for one individual interview each, at a time and location of their choosing. Second interviews with participants were not needed in this research as theoretical sampling did not guide a return to previous participants. In-depth, individual interviews were completed using an interview script and probes as a guide to the interviewer [NE]. The interview script and probes were developed with the intent to gain insight into the participants' worlds through their stories and receiving them with openness (Charmaz 2003; Charmaz, 2006). Interviews were scheduled to allow up to two hours in length to enable time for conversation. Although two hours was allotted for an interview session, the entire two hours did not need to be used if it was not necessary.

The interview guide (Appendix B) was formulated on the basis of open-ended questions in an attempt to avoid imposition of preconceived ideas on the participants' responses and emerging data (Charmaz, 2006). Interview questions that begin with 'tell me about', 'how', 'what' and 'when' are thought to yield rich data as the response is left open to the participants' conceptions (Charmaz, 2006). As such, these types of questions were reflected within the interview guide.

Open-ended interview questions were posed to elicit participant stories about the meaning of exercise, how exercise behaviour was influenced, and how exercise behaviour was formed through exercise participation. As understandings were formed with analysis of interview transcripts, interview questions and/or probes were revised to qualify and elaborate emerging categories through the insights of subsequent participants (Charmaz, 2006). Revisions to and further development of questions evolved out of the data for the purpose of theoretical sampling (Charmaz, 2006). For instance, it was becoming apparent earlier on that participants relied on HCPs in hospital or rehabilitation settings for exercise education and encouragement post stroke. Theoretical sampling was then utilized to further explore these ideas and whether or not this was influential to the process of continued exercise in the community. As such, questions around the idea of how individuals became involved in exercise post stroke were employed, which eventually lead to a core category. Questions were asked without the imposition of the

influence from HCPs, in order to remain open to any possibility described by participants.

3.4.4 Data Analysis

Consistent with grounded theory, data analysis was completed simultaneously with data collection (Charmaz, 2003; Charmaz, 2006). Analysis involved a constant comparison between data and codes, as well as new information with emerging categories to reduce knowledge gaps and formulate a proposed theory (Charmaz, 2006; Creswell, 2012). Interviews were transcribed verbatim [NE] and read and re-read to immerse the researchers in the participants' stories [NE, DC]. In grounded theory methodology, three types of coding were used in data analysis: open line-by-line coding, focused coding, and theoretical coding (Charmaz, 2006).

Line-by-line coding allows the researcher to remain focused on participants' views of reality, while hindering their own biases to construct meaning together from a constructivist paradigm (Charmaz, 2003). This type of coding allows for openness to all possible theoretical directions, and compares data to identify gaps which pinpoint the focus of further data collection (Charmaz, 2003; Charmaz, 2006). A sample transcript with coding line by line is provided in Appendix C. The realization of 'gaps' is part of the analytic process to continue data collection with a focus on areas where data is lacking (Charmaz, 2006). Focused coding was the second step of analysis within this study (Charmaz, 2006). The most substantial and frequent codes generated in line-by-line coding were organized into more precise categories to develop a greater picture that made analytic sense (Charmaz, 2003; Charmaz, 2006). For example, 'finding the right environment' emerged from initial codes described as motivating and stimulating factors to exercise such as, 'people', 'instructors', 'music', 'change of exercise', and 'fun'. Lastly, theoretical coding was utilized to formulate relationships between the categories formed within focused coding (Charmaz, 2006). Remaining consistent with grounded theory, this coding moved data in a more theoretical direction to propose a possible theory about the process leading to continued exercise participation in stroke survivors living within the community (Charmaz, 2006).

3.4.5 Memo Writing

Memo writing occurred throughout the research process to explore and elaborate on ideas and thoughts about codes and preliminary categories (Charmaz, 2003; Charmaz, 2006; Creswell, 2012). Memos were informal and free-flowing for personal use to advance thinking in a more theoretical direction (Charmaz, 2006). Memo writing was useful to define leads for future data collection through theoretical sampling as discussed above (Charmaz, 2003). Within this research, memos were written after the completion of an interview in order to write down first hand ideas of exercise participation as it was heard and understood throughout conversation, or to make note of preconceptions (Appendix D). Memos were written during and after interview transcription and coding to pull ideas together during analysis with respect to ‘processes’ described. Memos provided clarity of categories which were explored further for developing theory of the process described by study participants.

3.5 Quality

“The endpoint that we portray makes sense to us because we have been immersed in the process. For our audiences, however, lines become blurred between process and product”

(Charmaz, 2006, p. 181-182)

Data collection and analysis of a grounded theory study is concluded at the point of theoretical saturation, which may or may not make sense to readers, as they wonder why a particular study was ended at a certain point when determining the quality of the final product (Charmaz, 2006). Theoretical saturation is hardly evident in the research presentation; therefore, an explanation of the term is necessary as it is insufficient to state that saturation was achieved without understanding of the term (Caelli, Ray, & Mill, 2003). As such – and as stated above – theoretical saturation was recognized within this study as the absence of new insights or ideas arising in regards to the evolved categories (Charmaz, 2006). These recognitions became apparent through constant comparison of

data where core categories explained co-constructed meanings, and thus, further data collection through theoretical sampling did not yield re-formulation of such categories.

Given the variety of theoretical viewpoints in qualitative research, I provide descriptions of criteria applied throughout this research to enhance the quality of the study. It is suggested that in order to appropriately evaluate qualitative research, “enough detail about the study, the approach, and the methods needs to be involved” (Caelli et al., 2003, p.4). In this regard, I have provided explanation of grounded theory as well as my theoretical underpinnings and personal experiences for the reader to understand the approach used and to appreciate my position. Furthermore, the tools utilized to gather descriptions and develop theory are discussed.

Quality criteria for qualitative research and the associated paradigms were discussed by several authors including Caelli et al., (2003), Guba (1981), Guba and Lincoln (1994), Morrow (2005), and Tracy (2010). Additionally, criteria for the chosen methodology were presented, where Chamaz (2006) discussed the criteria for grounded theory studies. Moreover, Chiovitti and Piran (2003) discussed methods to employ as a means of enhancing rigor throughout a grounded theory research process. When taking into consideration all the quality criteria presented for each component of the research (e.g. qualitative research, constructivism, and grounded theory), consistent attention was paid towards trustworthiness presented by credibility and transferability (Guba, 1981; Guba & Lincoln, 1994). Additional attention was attributed to adequacy of data and adequacy of interpretation as described by Morrow (2005).

Methods to enhance credibility were allocated partly to the work of Guba (1981), as well as Chiovitti and Piran (2003). Peer debriefing was utilized during the research to enhance the criteria of credibility, where it is recommended for the inquiring researcher to detach themselves from the site of inquiry and debrief with other professionals (Guba, 1981). This was completed with my thesis supervisor [DC] through conversations pertaining to ideas and perceptions arising through participant interaction, and data transcription, as

described through brief memo writing. These conversations posed arising questions and important critiques for timely redirection of the inquiry (Guba, 1981).

Further, attentiveness to the suggested methods of enhancing credibility in grounded theory research was implemented (Chiovitti & Piran, 2003). These methods refer to allowing participants to guide the inquiry process, as well as articulating the researcher's insights. Preliminary codes were used to reflect the language of participants, which allowed the data to remain grounded in the participants' voice and the meanings they apply through what they describe, "so that the product of analysis could remain close to the primary data" (Chiovitti & Piran, 2003, p. 430). The codes formulated in this study through participant descriptions were added to the interview guide for further inquiry, which demonstrated the participant guiding the interview process (Chiovitti & Piran, 2003). Further, Chiovitti and Piran (2003) suggest articulating the researcher's position to enhance credibility. Within this study, articulation of my positional influence on the research is presented within 'statement of reflexivity' and was recognized throughout memo writing.

Further attention was focused on the criteria 'transferability', where I reject the notion of absolute generalizations or "truth" statements; rather, I believe that the interactions, descriptions, and thus, findings of this study, are context bound (Guba, 1981).

Transferability is thought to be parallel to external validity of quantitative research (Guba & Lincoln, 1994). In enhancing the criteria of transferability, Guba (1981) suggests collecting thick descriptive data and completing theoretical sampling in order to promote the development of thick descriptions. Data collection in this study allowed thick descriptions through the use of open-ended questions enabling paragraph responses, rather than closed-ended interviews with a short or single word response. Additionally, the participant population was not limited to the year of stroke or the effects of stroke, which enabled the collection of thick descriptions from a variety of participant type. Theoretical sampling was utilized in this research to explore emerging ideas and categories on information that was viewed as important and relevant (Guba, 1981).

Although theoretical sampling was not representative, it allowed exploration of uncovered information and enabled maximization of such information (Guba, 1981).

Adequacy of data and adequacy of interpretation are important to bring fullness to the criteria for trustworthiness (Morrow, 2005). Adequacy of data was not presented in the number of participants, but rather through the quality, length and depth of interview data (Morrow, 2005). In assessing adequate data, it is important to express the nature of the interview, where data collection in this study utilized a select few open-ended questions with a flexible interview guide (Morrow, 2005). A semi-structured interview guide allowed interview questions to emerge with the growing concepts imbedded in the growing data and emerging theory; thus, theory generation remained sensitive to data (Morrow, 2005). An interview guide with fewer questions available is thought to be more effective in enabling deeper understandings from participants, rather than several responses to several questions (Morrow, 2005). As such, the interview guide (Appendix B) used during this research contained eight questions.

Adequacy of interpretation is first attributed to being immersed in the interactive and constant comparative process with data collection and writing (Morrow, 2005). Articulation of the study design at the beginning of the research process, as suggested by Morrow (2005), allowed interpretation of data to be congruent with the chosen methodology (grounded theory). The analytic process was enhanced through the use of memos to recognize and present interpretations, and queries imposed in the data (Morrow, 2005). Lastly, adequacy of interpretation was demonstrated in the findings through the balance of researcher interpretation and supporting participant quotations, enabling readers to appreciate the interpretations as being “grounded in the lived experiences of the participants” (Morrow, 2005, p. 256).

3.6 Ethical Approval

Western University Health Science Research Ethics Board approved this study with an initial approval notice and an amended approval notice (Appendix E). Participants were provided with a Letter of Information (LOI) and consent form (Appendix F) pertaining to

the study, which discussed the study purpose, inclusion/exclusion criteria, participant role/duties in the research, and the dissemination of the research process. The LOI explained how interviews were going to be audio-recorded with the files being encrypted and stored on a password-protected computer. During interview transcription, confidentiality and anonymity was maintained through de-identification of participants with numeric coding. Participants were informed that all information is confidential and that the information expressed within the research would remain de-identified. Participants were informed that they could refuse to answer any questions or request for the interview session to be stopped. Furthermore, participants were informed that they could drop out of the study at any time prior to the study being published. After reading through the LOI, participants were free to ask the researcher any questions pertaining to the study. Each question was answered by the researcher to ensure complete understanding, enabling each participant to provide informed consent. Participants signed a consent form (Appendix F) to participate in the study that also highlighted whether they consented to the researcher using direct quotations within the research paper. The LOI was kept secured in a locked filing cabinet separate from the Master list of participants, which identified participant contact information for the purpose of conducting interviews.

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Chapter 4

4 Findings

4.1 Participants

Ten community living survivors of stroke agreed to participate in the study and each participant completed one interview (Table 1). Interviews were conducted in participant's homes (n=10) and ranged in duration from 40 to 60 minutes. Participants were recruited from community services that offered an exercise space (n=10), including community exercise centres and physiotherapy clinics. All participants reported exercising prior to their stroke, whether formally (e.g., attending the gym or community class) or informally (e.g., regularly golfing).

Table 1. Participant Characteristics (n=10)

	Sex/ Age	Years since stroke	Rehab Destination	Current functional effects of stroke	Current assistive device	Exercise Frequency & location	Re-join pre stroke exercise class?	Driving?
P1	F/76	2	Outpatient	Right hemiparesis, balance	None	3-5x/wk at facility	No	Yes
P2	F/73	2	Outpatient	Left hemiparesis, balance	None	3x/wk at facility	Yes	Yes
P3	F/89	2	Community	Balance	Cane	3x/wk at facility	Yes	Yes
P4	M/55	4	Inpatient	Right hemiparesis, spasticity	Cane, walker	Everyday at home	No	No
P5	M/56	4	Inpatient	Right hemiparesis, balance	Quad cane	4x/wk at facility	No	No
P6	F/87	1	Community	Left hemiparesis	None	Everyday at home	No	Yes
P7	F/89	1	Outpatient	Right hemiparesis, balance	Cane	3x/wk at facility	Yes	No
P8	M/69	2	Inpatient	Right hemiparesis	Wheelchair (primarily) Cane (short distance)	4x/wk at facility	No	No
P9	F/53	2	Community	Left hemiparesis, balance	None	2-3x/wk at facility, everyday at home	No	Yes
P10	F/53	9	Inpatient	Left hemiparesis	Ankle Foot Orthotic	1x/wk at facility, everyday at home	No	Yes

4.2 Process of exercise participation for the purpose of maintaining and/or improving functional recovery for people living at home with the effects of stroke

Participants described the process of exercise participation in the community for maintenance and/or improvement of functional recovery from stroke beginning after *initial exercise contact with a healthcare provider (HCP)*, followed by a *desire to improve post stroke life, navigating exercise opportunities* and then *commitment to exercise* (Figure 1). The process depended on time, not defined chronologically in weeks or months, but through improvements participants noted in their physical function with recovery from stroke and improvements in QOL. Participants moved through the process of recovery in physical function from stroke at their own rate. Descriptions from participants about how they moved and functioned before the stroke, or the things they used to do, were upheld as examples of the QOL they wished to regain. Exercise participation was described as a resource and a second chance to regain their former QOL before stroke. Quality of life was described as being “*whole*” again, like they were before stroke, where the deficits in function and QOL with stroke were recognized as negative factors impacting their “wholeness” of self.

P8: *[...] I want to be able to get my arm moving. I want to get my legs moving. I feel like – I sometimes feel like I’m half dead. My right side is gone. I want to get back as much as I can. We were joking the other day – a bunch of people from the gym, all in wheelchairs – one of them said, “well, we’ve all got one foot into the grave”. And I said, “yeah, its my right one”. So I’m trying to get that back. That’s what “whole” means. I have half of a whole. I want to get as much of that back as I can.”*

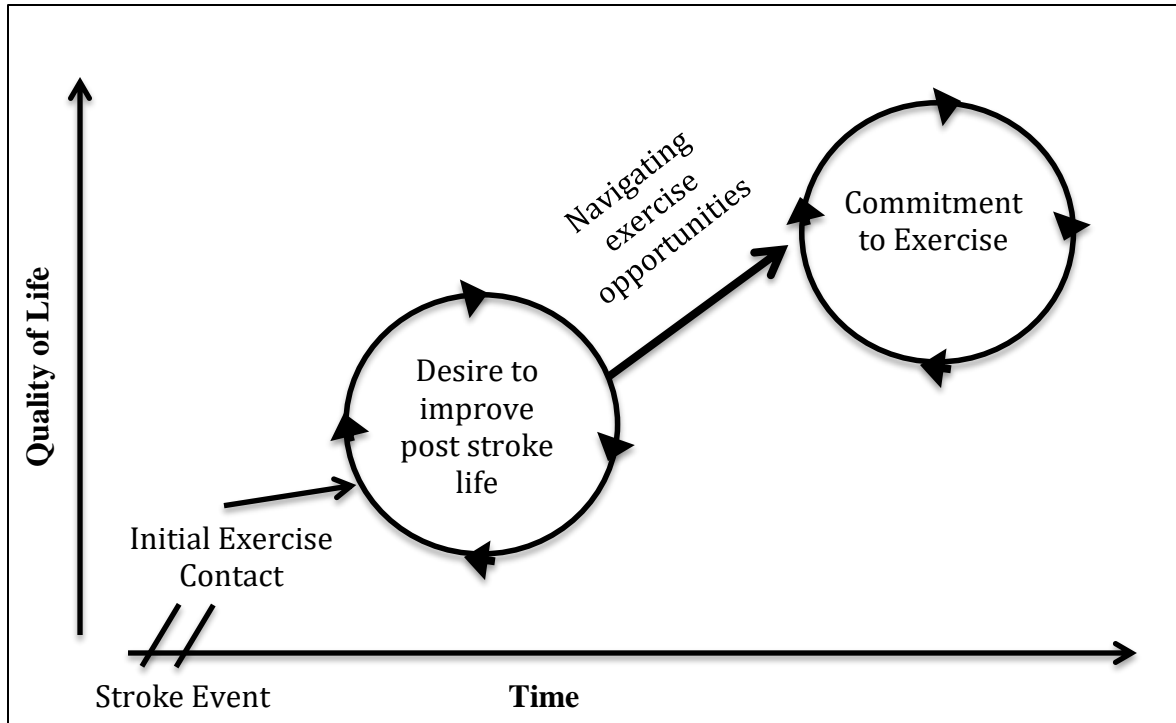


Figure 1. Process of exercise participation for the purpose of maintaining and/or improving functional recovery for ten adults living at home with the effects of stroke. The emergent theory of exercise participation began after *initial exercise contact with a healthcare provider* who educated, encouraged, and familiarized individuals with exercise. The *desire to improve post stroke life* required improvement in function, and was a strong and sustained influence for exercise participation as described in their plans to exercise to improve function. Individuals attained a positive attitude, compared themselves to their *prestroke* selves and others with/without stroke, became aware of health, and recognized future personal goals. Over time individuals *navigated exercise opportunities* as they connected with exercise programs in the community, and tried different types of exercise and exercise environments. Participants developed a *commitment for exercise*, which was supported by social groups, overcoming challenges to exercise, mastery of self care skills and improved mobility, and improved ability and pride in success. The process to achieve a commitment to exercise took time as participants regained QOL with recovery from physical impairments secondary to stroke.

4.2.1 Initial exercise contact with healthcare provider

In order to enter the process of participating in exercise in the community to maintain and/or improve physical function, participants described an initial exercise contact with HCPs as a crucial first step. Initial exercise contact is understood in terms of the first HCP who introduced exercise as part of recovery (i.e. first exercise contact), not necessarily the first HCP that they saw (i.e. paramedic or emergency physician). The initial exercise contact with HCPs during stroke rehabilitation was important for introducing and familiarizing participants with exercise post stroke as a means to improve physical function.

P2: *“I had the support from the hospital to have me get into the outpatients [rehab]. So that started me doing things and going along with all the OT and PT stuff.”*

P8: *“So I got on the fourth floor at [rehab facility]. I had regularly everyday, occupational and physio. So that’s what got me into it – that way! I was introduced to the gym gradually. When I was still inpatient, I would go to the gym to use the NuStep for about 15 minutes. That’s it. That was the only thing I was working on, besides trying to walk. But that was my introduction.”*

P5: *“I started at [hospital] and then when I was stable enough to be transferred, I did the physio for one hour a day and occupational therapy for one hour a day and speech therapy one hour a day. So there, I learned foundations of good exercise [...] There’s nothing in the exercises that I didn’t either learn in the hospital or see on the videos. So I’m copying those exercises. I don’t think there is anything here that I made up on my own. Just on the top of my head. Yeah, the two main sources were physiotherapy and YouTube and a little bit of recommendations from [facility].”*

P6: *“I would say, if he [referring to physiotherapist] hadn’t come to my home, I don’t think I probably would have done it. You have to be shown how to do it and*

then appreciate – goodness, it’s so simple looking at those things [referring to exercise sheet] –they become very difficult when you do them right. And you would not do them right without him coming – or a physio coming to teach you.”

P9: *“I saw the biggest improvement probably during the six months when the lady from the stroke team came. She knew what activities to have me do to build my balance and my strength and my endurance.”*

Further for Participant 4, the initial exercise contact with his doctor was important in shaping his definition of what constituted exercise. *“My family doctor has been the biggest one saying that ‘you gotta break a sweat; you can’t just walk down the road. That’s not exercise. Its when your heart rate gets up right enough that you break a sweat’.”*

Healthcare providers played an important role introducing participants to exercise within day-to-day activity, exercise options, and the reasons for exercise as part of lifestyle, as well as providing guidance for future exercise behaviour. Participant 7 noted how important her initial exercise contact was with an HCP in promoting exercise and the appropriate steps to take which gave her confidence to take on other forms of exercise.

“Well walking is amazing. You tend to take very short steps when you first start. And she was always trying to get me to walk with my heel down first and a big broad step rather than a smaller one. So I practiced that, and once I got off the walker, I had the tendency at first to just drag my foot here at the apartment. But there’s a circle out here, so [my husband] and I would go out and walk around the circle two or three times, until the weather got poor. So, it was nice to have the exercise at the arena, because I can’t go out walking now [in bad weather].”

Furthermore, encouragement from an HCP and integration of an exercise program provided by HCPs was recognized by participants as a pivotal moment to commence and increase exercise participation on their own time in the community.

P9: *“So right after the stroke, the community stroke team came and she set me up on a program. It was huge the things she was able to work with me to build up – my walking again – and build up my endurance. And she encouraged me. She came two days a week, sometimes three days a week, and then she encouraged me to exercise on the days that she didn’t come too.”*

When being discharged from hospital, participants felt HCPs were important for bridging/connecting formal rehabilitation with continued exercise participation.

P10: *“Well at first I couldn’t do anything, right!? I had to learn how to walk. So I was in [rehab facility] for three months and then I had physio for about three hours a day. So that was part of the exercise there. And then when I was discharged, I was referred to [physio clinic], and started doing the physiotherapy there with of course exercises. And they give you exercises to carry on at home. So I would do those and then come back. So I kept that up that way.”*

When asked how she got connected to community services, Participant 10 stated, *“[Doctor] who is the neurologist at [rehabilitation facility] suggested to me, “why don’t you go see [PT]? “She’s the best!” So you know, I hooked up that way and just went to her.”*

Initial exercise contact with an HCP was important for introducing exercise, guiding exercise behaviour, and encouraging continued exercise on non-rehabilitation days. Participants described how they re-established previous beliefs or created a new understanding about exercise within their current experience as a person living with the effects of stroke. Initial exercise contact was crucial for participants to begin exercise participation in the community, and further encouragement to try other activities outside of exercise led by an HCP.

4.2.2 Desire to improve post stroke life

Following the initial exercise contact, participants moved away from introductory exercise and began to describe the role(s) of exercise for them ‘self’ and what they

desired to achieve with exercise. The *desire to improve post stroke life* was told in stories about improving physical function to get better and return to things they used to do. The *desire to improve post stroke life* was described as plans or intentions for exercising to achieve improved function, which consisted of four influential factors: having a positive attitude, comparing their current self to pre-stroke self and other people with/without stroke, having personal future goals, and awareness of health.

4.2.2.1 Positive attitude

Participants described exercise participation using positive language, which seemed to be based on the knowledge acquired during the initial exercise contact with an HCP and development of a positive attitude towards exercise. Participants formulated a positive attitude for exercising based on their trust in the education and encouragement received from HCPs. The positive attitude stimulated an intention to continue exercising, where it was believed that exercise was going to help them get better.

P4: *“When I was at the hospital, they had me on the treadmill and they said, ‘you gotta keep moving. You will get better. It will get better’. So I felt like that’s what was going to make me get better.”*

P4: *“Whatever doctors suggested is the reason I try to do things. Like, a lot of the research is on their side, so I try to do the best for whatever they suggested.”*

Participants trusted the recommendations of their HCPs, which influenced their attitude to exercise. When asked why he started exercise post stroke in the absence of exercise activities during pre-stroke life, Participant 5 trusted the information provided to improve his condition.

P5: *“My physiotherapist said it was a good idea to put 30 minutes of daily exercise at the minimum.”*

4.2.2.2 Comparison to previous self and others

Participants referred to their life and function before stroke as a marker of improved QOL and expressed their strong aspirations to return to their life and previous levels of function. They recognised that it would take hard work to return to life and function before stroke, but were unsure how realistic it might be to get back to their *pre-stroke* self.

P10: *“I’m a competitive person – so trying to get back to what I was, which I know will never happen...”*

P9: *“I think just to be a little bit stronger than I am now. Trying to get back to where I was before. That may never happen, but I think if I keep working towards that, then I’ll be able to maintain. Through a stage of life where most people tend to start losing strength.”*

P5: *“My goal is full recovery – now, that’s not practical anymore, because it has been 3 years exercising, 3 and a half years since my stroke. So I know I’m always going to walk with a limp and talk funny, but I’m trying to get more use of my arm and leg. Because it is – you can’t tell right now, but it’s really weak. So that is my goal. And that is the idea of exercise that it is a means to an end.”*

P1: *“...since the stroke, there are a lot of things that are still wrong. My leg doesn’t work the same way. My fine motor skills are terrible. As you can hear, my voice – its changed a little bit. So there’s a lot of things that are still wrong that I want to improve. I want to get back to the way I was. I don’t think it’s going to happen to tell you the truth, but I would really like to get back there.”*

Participants talked about their previous selves when describing how they intended to be physically independent through participation in exercise and when speaking about the effects their stroke had on their function.

P3: *“...it is more difficult for me to exercise because the consequence of the stroke was that my balance was affected. Now, it wasn’t even badly affected, so I’m not complaining. But affected enough that when I walk – I walk with a cane*

now – but when I walk at the centre, I don't use a cane. But I certainly wobble a lot. Which worries other people more than it worries me, I expect. But, it takes more effort to actually do the exercise [...] I wasn't that fit before, because I have had a hip replacement. I do have arthritis in my hip. So, walking has been increasingly difficult and is painful. But my balance was alright. Now it isn't."

Participants remained realistic in their goals of achieving pre-stroke self rather than achieving goals they had set prior to experiencing a stroke. Participant 8 expressed the desire to return to pre-stroke ambulation levels of walking with a cane rather than previous aspirations set out to improve quality of ambulation.

P8: "Before my stroke, I was going to get my knees replaced, because I have osteoarthritis in the knees. I've got bone on bone contact in each knee, three places. So I was going to get both knees replaced. So, as a consequence of that, I would walk with a cane regularly before my stroke. So now, I want to be able to walk with a cane. That would be fine for me. That is probably as good as I'm going to get. But I'm working towards that."

In addition to comparing post-stroke self to pre-stroke self, some participants spoke about comparing themselves to other individuals as a motivator to improve their post stroke life. Comparison to others promoted the plan to exercise to get better and occurred in the context of the exercise program(s) they previously attended prior to stroke, or currently attend as a momentary exercise option.

P2: "[speaking about exercise group she previously belonged to] And you know quite honestly, there are some of them there who are in their late 80s who are in better shape than I am. And I don't mean since I have had a stroke. They have just always been very active people. So, it's very good from that view point – you kind of can't let someone who is 10 years older than you outdo you. So you keep on doing."

P9: “...there’s another guy there who is [elderly], and he is just amazing. I’m probably close to his level and above many of the others, but not – so I keep an eye on him and I try to work as hard as he does. He runs marathons.”

4.2.2.3 Personal future goals

Recognition of personal future goals, for example, improvement/maintenance of physical function, independence in day-to-day activities, or doing things they enjoy, where the achievement of goals depended on functional ability, was influential in the *desire to improve post stroke life*. Participants wanted to exercise to achieve something through improved function. Participant 8 spoke about his goal for independence living at home with minimal reliance on others,

“I want to perform my functions to the best of my ability without having to rely on other people. I want to be able to go into my room, sit down where I want to sit, and do what I can do. I want to go into my backyard and walk around my pool. I want to get into the pool. So, having said that, to back track a little bit – when I came home from [hospital], my wife had to do everything for me. I couldn’t even wipe my bum. Now, I can get myself dressed, I can shave, I can do all the things that I used to do. And that’s the kind of thing that I’m so motivated to do more.”

Participant 4 wanted to ride his bike again someday.

“I’d like to ride my bike again. I got a bike just before the stroke happened. I got a brand new bike, and I’ve rode it twice. It’s still out there in my shed. This therapist said, ‘use it, if you don’t like to use the walker. Just walk down the road with that new bike’. And that’s what she has told me to do. ‘If you need the extra support while walking down the road, just walk down the road with your bike’.”

Participant 9 recognised that her strength was much lower than her pre-stroke self, and held a personal goal of maintaining her strength as best as she could within the natural aging process.

“I think just to be a little bit stronger than I am now. Trying to get back to where I was before. That may never happen, but I think if I keep working towards that, then

I'll be able to maintain. Through a stage of life where most people tend to start losing strength."

Participant 3 spoke about her personal goal of being able to do what she wants when she wants in response to being asked 'how exercise fits into her life and the perceived benefits post-stroke'. She believed that exercise would help keep her functioning so she could do the activities she loves.

"Well, I am certainly able to go places that I want to go. We often travel. And, for example, last spring, we were in Australia. Not sure what the future holds for travel, because my husband is quite elderly – he's [age]. He's also a member of this walking group. He hasn't shown much interest in traveling right now. So we may not travel. But I want to be able to travel if there's an opportunity."

4.2.2.4 Awareness of health

Participants became much more aware of their health. It was clear in conversation that they had spent time thinking about the stroke and had spent time in reflection. Reflection on their health-related concerns enhanced their awareness to help improve their current health status and support exercise participation to achieve their goals. Participants wanted to live a healthier life. The importance of improving health and mobility was seen to promote independent function for higher QOL. Participant 1 became more attuned to the concept of health when she reflected on the cause of her stroke, which she blamed on weight gain. Exercise was now seen as a means to assist with weight loss in an attempt to achieve a healthier version of her post-stroke self.

P1: "I lay a lot of the blame on my stroke to – you know, middle age, you start putting weight on and everything – so, I look to the exercise to start taking off that weight. [...] If you don't improve your health, if you start falling back – and apparently that's what I must have done to have a stroke in the first place – you're just making your life shorter. So I'm trying to get myself back into a healthy relationship."

Participant 5 reflected on his health status prior to stroke and how it may have contributed to the stroke. He recognised he had an opportunity or a ‘second chance’ at life after stroke and he needed to be more physically active.

“My BMI was more than 30. So, not morbidly obese, but obese. So I didn’t do anything – well I would go to the cupboard and eat some cookies, so that was exercise from the couch to the cupboard (laughing). But no, I didn’t do anything. So the four months in the hospital, I said, ‘well, I’ve got a second chance at life’. Because it was really a brain aneurysm and some of the doctors said months later I should have been dead before I hit the ground. So, I figured I’ve been given a second chance and so – just to work at it.”

Reflecting on the recent passing of a friend, Participant 2 spoke about her awareness of health through the adage ‘use it or lose it’. The loss of her friend and the effect of her friend’s death on family seemed to be an encouraging influence on Participant 2 to keep moving herself to maintain and improve her health for herself and her children.

“...If you don’t use it, you lose it. And I would never in a million years have believed it. So, I knew this before, and I tried to get him to keep moving – but that is – absolutely in here, that is embedded in my head. I will not not keep moving. I will keep moving. Because, if you can deteriorate that much in those few months, just because of your lack of – and mental attitude – pfft, ain’t going to happen to me. I’m not going to put my children through that kind of stuff. Won’t do it.”

Participant 4 talked about his reading of the research to enhance his knowledge about and the role of exercise for health and recovery following stroke.

“I read a lot of the neurology stuff that you gotta keep doing it repetitively to get your muscles and stuff to re-wire. That’s one of reasons why I keep going. If you don’t do it, then you’ll never know. So I keep going thinking that maybe it will get better.”

With the self-education piece, Participant 4 further commented on how exercise will help get him better by stating, *“It helps re-wire the brain patterns that were damaged. They know that’s what needs to be done. So I keep doing it.”*

4.2.3 Navigating exercise opportunities

Navigating describes elements of the participants’ stories about exploring exercise options to see what worked for them and what did not work for them. Navigation acted as a bridge between the *desire to improve post stroke life* and *commitment to exercise*. Through the process of navigation participants explored exercise programs and resources to work on their physical functional goals and improve their QOL. Participants spoke about navigation as a ‘trial and error’ as they tried different types of exercise on their path of commitment to include exercise in their life. Participants spoke about seeking and connecting with community exercise programs, as well as exploring different exercise environments that would foster their exercise participation. Some participants commented that being discharged from hospital or inpatient rehabilitation, and a lack of outpatient rehabilitation services, initiated their search to explore options for exercise participation. Some participants re-connected with a familiar exercise program or facility.

P2: *“[...] I was really hoping to go to inpatient rehab at [hospital]. Unfortunately, I was too mobile and too good to do that, so I got outpatient rehab for 8 weeks [...] Anyway, I did the 8 weeks, and when it was finished, I contacted the gal who was the exercise coordinator at [community facility] to say, “can I come back? Is this going to create a problem for the class?” And that’s when she said, “no, you go ahead.”*

P3: *“When the services here stopped, and they do stop after a certain point, I realized that I had to then put something else in place. And of course, my walking group had been there for so many years, that was the place I returned to.”*

Similarly, Participant 7 indirectly recognized her husband’s influence to re-connect with an exercise group when she stated, *“we have quite the little group here. My husband was going all the time so I started going back”*.

Participant 8 expressed re-connecting with the gym facility in which he completed outpatient rehabilitation.

“I couldn’t wait to get back to [previous outpatient facility centre]. And they took me back for another couple of months and then gradually – I got a chance to go into the gym for the 4-6 four times a week. But there’s a waiting list, and I finally got off the waiting list to go to the gym four times per week. I took that and ran with it because I wanted to keep going and get better. So I go four times a week from 4-6.”

In circumstances when participants did not have an exercise facility to re-connect with, they sought their own new exercise opportunities. Participant 4 spoke about different exercise programs that he tried. *“I did swim therapy at the community pool. I did – I went to [facility] and did a yoga class there. I was doing – I walk down the corner of the road and back. So I was doing that sort of thing too. And then I tried – I know it wasn’t really breaking a sweat, but I would garden and stuff.”* Also, because Participant 4 lived in a very remote community, he explored exercise opportunities through the use of technology. He spoke about online exercise programs, and how he became connected with a Fitbit group and a group on Facebook: *“I’m part of a stroke group on Facebook and then I’m also part of an individual exercise group. It’s – we just call ourselves the ‘Fitbit fans’. We all have a Fitbit [...] You type ‘join a group’, so I typed in ‘stroke’, and it was the only group that came up part of stroke”.*

The notion of *navigating* included descriptions from participants about finding the right social environment for participation in exercise. Finding the right environment was described through motivating factors. For Participant 1, finding the right environment with friendly people was a motivator to attend exercise classes in the absence of enjoying exercise itself.

“I don’t seem to get the real buzz from it that she does. But, it’s such a nice place to be. The instructors are so upbeat and happy to see you. And the people – most of them really seem to have a nice point of view. They are upbeat too. And they are

kind of in the same position you are too. So you get to be quite friendly with them. And happy to be there.”

In addition to friendly people, having fun during exercise class was a motivating factor. Participant 3 participated in exercise for fun, *“Well I think the fun aspect of it. You know when you’re playing with balls and bands, there’s certain aspects of it that is child like. And that’s fun.”* Cost and location were important for Participant 9 as she explored her options and found something suitable.

“A key factor for me was that it was close and because I didn’t have to pay. I didn’t want to pay for something and then find it to not be at my level. So I can go, and I can try it, and I can keep going if I want to, but there was no attachment there and no financial cost. It’s not like you had to pay 100 bucks or whatever. So that was an incentive for me to go and try it.”

Despite owning a treadmill at home, Participant 2 explained the need to navigate other exercise opportunities as she re-connected with a facility for participation in exercise. For her, a change in the approach to exercise was important.

“I have a treadmill downstairs, and I don’t go on it very often. It’s there, but I have to be watching TV or something if I’m going to go on it. I just do not find going on a treadmill exciting at all. Even the exercising at [facility] – as long as there’s changing up, there’s lots of times where, “Oh, that time went fast”. But it’s because we had been changing doing what we were doing. And I do like sporty things. I like dancing and stuff like that from when you know – but, as long as you are moving to music and what not.”

In some instances, it was apparent from participants that the presence of an instructor was integral to attract them to a facility and to promote exercise participation. Participant 7 stated, *“I’m not too very good at doing it on my own, I must say. I’ve always been used to having someone in front of me telling me what to do. So I don’t really think that I would do too much actually [on my own].”*

The instructors themselves were described as motivating factors by participants secondary to the variety of exercises provided, and how they kept exercise interesting.

P1: *“I think you could get a little bit bored if they always kept it the same way [...] And of course they have three instructors too. And the instructors take different days. And hey each do their own little vibe on the exercise. So it’s always a little bit different that way too. And some have a bit more energy, or the movement seems a little bit quicker with that instructor compared to the other instructor.”*

Although the majority of participants preferred to exercise within a socially stimulating environment, Participant 5 expressed his desire to exercise on his own as it allowed him to fully complete exercises at his own pace. He initially tried exercising in a group class setting, however, was required to navigate other exercise program options to achieve the effects he desired from exercise.

P5: *“Well, it’s basically a glorified day program [...] They have an exercise class from 10 – 11 and from 1 – 2, mostly to do with arms. And the one from 10 – 11 is mostly to do with legs and cardiovascular. So they split it up, but I haven’t gone to that in two years because it’s just too fast sometimes. They’ll do 15 of something and then they will go on to something else. And I say, “hey, I have done 7 of these. Slow down.” I shouldn’t be that anchor, or weight – so I let the class – I realized I have to let the class go at their own speed [...] I just went off on my own.”*

4.2.4 Commitment to exercise

Participants described committing to exercise after *navigating* through exercise opportunities and finding an environment and/or program that stimulated their desire to participate in exercise. Participants signalled *commitment to exercise* when they spoke about continued exercise participation, accountability for exercise participation, and seeing the impact of exercise participation with their improved function and QOL. Participants noted positive functional gains and QOL with continued exercise and described themselves as becoming more ‘whole’. In the process of committing to exercise, participants spoke about social relationships, overcoming challenges to exercise participation, pride in their successes, and mastering of self-care skills.

4.2.4.1 Social relationships

One of the more influential factors contributing to participants' commitment to exercise was the development of social relationships at exercise classes. Participant 3 remarked, *“if there was no social component, I don't think it would be as appealing. If it was just straightforward exercise and you didn't get a chance to chat and have some fun with people. But I can't see a group of human beings not make social connections. I mean, it is our nature.”*

As participants continued with exercise participation they became more committed to exercise. Participants spoke about belonging to a group or facility that fostered their commitment.

P8: *“The people there are quite – the other clients – we have a really good time. It is a very sociable and supportive group. Even if I'm not feeling good, they make me feel better.”*

P2: *“...going back after my stroke – I have a lot of friends there after all those years. So, there were a lot of people concerned about me having had a stroke, so it was kind of nice – they were very supportive. I keep being told, “oh you're doing so great! Oh, you're doing so well!” So I think that helps keep on with the exercising.”*

P4: *“...we have this group – its called “challenge” – and it's just for the week... – and we can cheer on everybody every day. We can look on there and click on the person, and “oh good for you! You got your step going!” We each have step goals. So that's part of an initiator too, ‘oh Geeze, I'm way behind! Wow!’”*

P3: *“...the other people are interesting. Some of them are quite witty, so that helps – you get to laugh a lot.”*

Not only did social interactions keep participants engaged in exercise, they provided support for lifestyle change as exercisers and support for developing new or returning to

former interests and hobbies. Participant 1 described, *“they get me interested in restarting what I did enjoy in life”*. Feelings of belonging and nurturing, not only for exercise participation, but other aspects of life were described by participants as supports to return to a former social group and/or exercise class.

P3: *“Well, I find I am more likely to go because of the people. I enjoy meeting them and talking with them. We have a book exchange situation, so we are always sending books back and forth. And I certainly am much more likely to attend a group like that than to do something on my own.”*

P1: *“Well they have a lot of things that I like. They have the exercise program, plus they’ve got all the other equipment that you can do by yourself – like the treadmill, etcetera. So there is always that around. They’ve always got a puzzle on the go. I like to work with puzzles. So there’s always that to do. They do a lot of – every month, they try to have something different there that you haven’t done in the previous month. Like we play bingo every Friday for maybe a month or two [...] They got painting classes, and I was a painter and so I really – basically, they’re the ones that got me back into painting because I just felt with my arm, I couldn’t do it at all. And they were quite – showed me you can go abstract, you don’t have to be a detailed painter. So they started me back doing that.”*

4.2.4.2 Ability to overcome challenges to exercise

The effects of living with a stroke imposed challenges to exercise participation. For some participants, challenges to exercise participation included having to modify exercises so that they could be adjusted to their ability for movement or to compensate for impaired function following stroke. Accepting their level of ability and adapting exercises to their current ability demonstrated a high level of adherence to exercise by participants.

Participant 4 described a challenge they faced for exercise participation.

“There are times I can’t even get out of bed. Just from the spasticity in my body, I can’t even get out of bed. We even purchased one of those urinal containers, because I am that bad some days.” However, despite the challenge to exercise on any given day, P4 recognized the need to do something over nothing and spoke

about his perseverance, *“I know I gotta do something. Something is better than nothing. So that’s why I have two little 1lb weights – they’re just little dumbbells, and I lay in bed and I do it. I know I gotta do something, or else”*.

Secondary to decreased strength, Participant 2 changed her mat exercise program so that she could complete it sitting on a chair.

“We do aerobics and cardio and weight and balance and mat work. Now, I’m not doing the mat work. I’m doing it on chairs – what I was doing on mat – because it is hard for me to get up right at the present time from the mat and be leaning on my left arm as well as my right arm.”

Participant 3 spoke about the alterations they made to enable them to complete a balance exercise to accommodate for the effects of stroke on their general balance.

“... the balance exercises that we do every time – variety of things that we do – I do them, but most of the time I try to hold onto a railing. There’s a railing in the gym because I don’t want to fall. And, I’m at risk of falling. So, as I point out to them, you don’t want to have a dead camper on your doorsteps. So I do try to do balance exercises, but I modify them according to what I need.”

Some participants needed to incorporate intermittent rest breaks to ensure optimal performance of exercises secondary to the effects of fatigue from stroke. The moments where participants allowed their body rest were important for preventing burnout, and therefore, supported adherence to exercise participation.

P3: *“... I can work on the machines – the weight machines. I can do the chair exercises. I can do the warm up and cool down. But in the middle, the exercise is often very rapid, and I – I just can’t do much of that. So I do as much as I can – maybe a few minutes of that kind of exercise, and then I rest [...] I try, but I’m not going to damage myself. And when my body says, “look I have had enough”, I sit down. I’ve had enough.”*

P9: *“I try to work it until I’m tired. Until there is a level of tiredness that isn’t manageable. Since the stroke, that is one thing I learned – if you get over tired, that’s really not good. It takes a few days to get out of that cycle. I work until I get to a certain level of tiredness, and then I have to sit down and rest. And that’s something that I have learned over the last couple of years – you just have to do that.”*

Participant 9 supported these insights of other participants about fatigue with stroke. She had to figure out about conserving her energy for the exercise class, rather than putting effort into her physical appearance for example, so that she could complete the activities most important to her on that day.

“Most often it’s fatigue [...] There hasn’t been too many times, but it tends to be fatigue that stops. But other than that, it’s a very open class. It’s not something that you would be afraid of what you’re wearing, or afraid of what your hair looked like or something.”

Some participants were faced with the challenge of not being able to drive themselves to exercise class, and had to actively plan for transportation to class. Transportation arrangements made to attend exercise demonstrated how participants prioritized exercise participation and were actively being adherent to exercise in their lives.

P5: *“...my friend – she drops me off at 8:30 and the caravan, disability picks me up at 12:30 [...] So that’s a daily routine that I developed Monday to Thursday.”*

P8: *“Now I take the [transit], and to go from here to [exercise facility]. I have to arrange it for 2:30, so it can be sure to get there for 4. So sometimes I get there early. Sometimes, not so good. But for the most part, if I get picked up at 2:30, I will get there in time to get a coffee and then wait for the gym.”*

An exercise schedule and the routine of attending exercise class was portrayed as providing structure to day-to-day activities. Many participants described their exercise schedule as the focus when organizing their daily and weekly activities, which promoted

perseverance to exercise in the presence of a challenge. Exercise participation became a part of their day-to-day lives and offered them a sense of fulfilment.

P1: *“I know that’s the only way – I hate to do exercises by myself, I just wouldn’t do it. The days that I don’t go, I try to get out and do a walk around the block. But a lot of times, I don’t [...] if I don’t go [to class], I know I’m not going to do it. So it’s the incentive to get there.”*

P3: *“I know that Monday, Wednesday and Friday are exercise days. And so in the morning, that’s what I plan to do. And most times I do. And if there are other things I have to do, I make sure they are later in the day. So I build it in. It is part of my schedule.”*

P8: *“When Mondays come, I’m excited. I’m going to the gym. Tuesday, I’m not so excited, because I can’t go to the gym because it’s closed. Then Wednesday, it’s like starting the week over again, and I’m excited. And then Thursday, it is a routine. And Friday is like when you’re working – it’s just Friday! So, I’ve never been discouraged about going. I have always been excited to go, and a little bit sad when it’s finished.”*

P7: *“I just feel so awful if I don’t go, knowing that I could have gone. There are – you know, you don’t have that many classes to go to. If I stay home and knew the class was going on, and I could have gone, it would bother me.”*

4.2.4.3 Mastery of self-care skills and improved mobility

Increasing mastery of self-care skills and improved mobility through exercise fostered *commitment to exercise* by participants. For Participant 2, increased muscle strength from exercise improved their ability to perform self-care skills and improved her ADLs.

“Well it’s really getting more flexibility. Getting all the muscles – for instance, in my arm, I couldn’t touch finger – thumb to finger like this (participant demonstrating action) before. And now I can. I mean, I’m not good at it, but I can

do it. I can do up a zipper, and I can get dressed with no problem. And fold clothes. The only thing is, fitted sheets, I still have trouble with.”

Participant 1 explained the act of re-introducing cooking into her life as she became stronger with increased agility, which she attributed to exercise participation.

“My husband – he was doing all the cooking for quite a few years. And, so this last year, I basically told him that I want to get back into the cooking. And so, now I do three nights. And so, you know, if you have Chinese food, and just all that chopping – it’s surprising how much strength and agility that takes.”

4.2.4.4 Recognize new ability and pride in successes

Commitment to exercise was exemplified by stories from participants describing how they recognised new abilities achieved through exercise participation. Their accomplishments were a source of pride.

P1: *“They have a little test that they put you through. I think it’s every three months. So I’m now in that program. So they test you, and three months later, they do the same test again. Well, I almost doubled what I did the previous one, so I was very very pleased and impressed.”*

P10: *“Well for sure I feel healthier getting involved with the exercise. It makes me feel like I can do a few more things. Like I do notice a difference too for sure in the leg strength. Like in this house, there’s a lot of stairs – front and back there – and before, it would be like, “oh I’m only halfway up”. And now I can get up and down the stairs easier. Again, with practice right. And just doing that.”*

Participant 8 was so proud when he described achieving some of his initial goals related to his ability for self-care. *“Now, I can get myself dressed, I can shave, I can do all the things that I used to do. And that’s the kind of thing that I’m so motivated to do more.”*

His pride in his newly achieved abilities seemed to deepen his *commitment to exercise* in order to accomplish other goals he held. Participant 8 spoke in detail about his latest achievements attributed to exercise participation and his next goals.

“Lately, I have been putting the bed in the lowest position so that I can stand up from that, to practice for my couch,” and

“Recently, I’ve been doing the steps in the gym. Walking up the steps five times – five steps, then backing back down. Because I want to – I have a pool in my backyard that has steps into the water. I want to go into the pool this summer.”

Similarly, Participant 10 spoke about the impact of their achievements and pride in accomplishments that occurred with exercise participation reinforcing their *commitment to exercise*.

“I have just gotten better and better from the beginning. When I think about where I started from – where I couldn’t even sit up on the edge of the bed without support, or getting to the bathroom. So now I’m just so independent – that in itself is a motivator. You just want to keep going.”

Exercise seemed to become a part of participants; who they were and what they wanted to become. It was suggested that through continued improvements, they had incorporated exercise into their daily living.

P8: *“If I am having breakfast and reading the paper, and I have to go to the bathroom, I’m thinking about walking, and that’s part of my exercise. So I think about ‘where am I going to park my wheelchair? How far am I going to walk?’ So, it’s ingrained in what I’m doing. Everything is exercise.”*

P10: *“If I’m waiting for water to boil or something, I might just stand in the kitchen and do 5 or 6 (speaking of completing squats) [...] And then when I let the dogs out, when I go downstairs, I’ll sit on the steps and do some leg lifts and different things while I wait for them to come back in.”*

Furthermore, Participant 9 and Participant 10 spoke about their *commitment to exercise* when describing their increased ability and sense of pride to independently walk.

Exercise was re-enforced by challenging the terrain for future improvements.

P10: *“Like walking on a path is easy – like a paved path – but if you go to the grass, it’s a little more uneven. I find that challenges me a little more. It doesn’t always feel easy and fast, but sometimes speed isn’t what it’s cracked up to be either – it’s technique. That’s the whole premise – if you challenge yourself, then you get better.”*

P9: *“I don’t mind to go through a little bit deep snow because that is actually a good workout to do that too! So that’s what I usually do.”*

Chapter 5

5 Discussion

This study explored the process of exercise participation by survivors of stroke living at home in the community as a means of maintaining and/or improving functional recovery. Although findings of this study are contextually linked, and therefore, not ‘generalizable’ to the broader population, the new understandings of exercise participation for functional recovery by people living with the effects of stroke from this study will be helpful to support continued recovery of this group of people. New information from this study includes the importance of an initial exercise contact with an HCP to initiate exercise participation, and thus, promote and enhance long-term health outcomes and recovery. New understandings described the attracting features of community services to promote long-term adherence to exercise participation by people living with stroke in the community (i.e. activities to nurture lifestyle). The findings of this study provide understandings to the term ‘intention’ described in behaviour change models such as TPB and PAD Model (Ajzen, 1985; van der Ploeg, van der Beek, van der Woude, & van Mechelen, 2004). Moreover, insight into the ‘intention-behaviour’ component of behaviour change models was provided, where the transition from intention to behaviour may be described as ‘navigating’. These insights were specific to people living in the community with the effects of stroke, as described by participants in this study. Findings provided insight and understandings about *how* people living with the effects of stroke continued to participate in exercise for maintenance and improvement of function. The process involved transitioning through a series of phases beginning with *initial exercise contact with a HCP*, followed by *desire to improve post stroke life*, *navigating exercise opportunities*, and *commitment to exercise*. Time was not defined by participants chronologically (i.e., weeks or months), but rather, was marked by improvements in physical function and recovery from the effects of stroke. The process to achieve a *commitment to exercise* took time regardless of whether participants were physically active prior to stroke or not, and was influenced by severity of the sustained stroke. Participants moved through each of the four phases of exercise participation depending on their individual recovery from the physical impairments from stroke. The findings of this study were supported by the literature whereby improvement in QOL was found with

enhanced functional recovery (Clarke, Lawrence, & Black, 2000; Gbiri & Akinpelu, 2013). In this study, exercise was a major factor in achieving improved function and QOL, which was supported by Murtezani and colleagues (2009). The stories from participants about their *desire to improve post stroke life* and *commitment to exercise* yielded tangible examples of improved QOL whereby participants felt more like themselves and revelled in their increased independence with everyday tasks of daily living.

Although impaired cognition and motor impairment during stroke recovery was described in previous literature (Quaney et al., 2009; Verstraeten, Mark, & Sitskoorn, 2016), none of the participants in this study described concerns with cognitive impairment following stroke. Perhaps this was because motor impairments were more obvious to people living with a stroke as highlighted by Verstraeten et al. (2016). Alternatively, perhaps survivors of stroke were not aware of the benefits of exercise for cognitive function. The current study provides a foundation for supporting exercise participation in clinical practice.

5.1 Initial Exercise Contact

The process of exercise participation for the purpose of improved function began with a positive initial exercise contact with an HCP. This contact was seen as pivotal to initiate participation and contribute to participants' intentions to exercise for health benefits by promoting a positive attitude. It is already known that HCPs play an important role in exercise promotion, where previous studies described the impact of a strong therapeutic alliance in shaping the engagement of and motivation for rehabilitation in the general population and people living with stroke, as well as promoting successful health outcomes (Bright, Kayes, Worrall, & McPherson, 2015; Lawton, Haddock, Conroy, & Sage, 2016; MacLean, Pound, Wolfe, & Rudd, 2002; Stewart, 1995). Findings of this study provide new understandings that the initial exercise contact with an HCP was essential for long-term exercise participation, health, and recovery, as exercise and its associated benefits was not commenced without initiation by an HCP. Findings also highlight the importance of HCPs in introducing, familiarizing, guiding, facilitating, encouraging, and recommending exercise opportunities. HCPs played the role of

educating participants living with stroke about the required level and intensity of exercise to influence functional change, types of exercise, and guidelines for engaging in exercise. This study provided knowledge regarding the timing and implementation of HCPs as a social facilitating factor along the continuum of exercise participation.

5.2 Desire to improve post stroke life

Following initial introduction to exercise, participants began to take a more independent role in the process of exercise participation after discharge to home in the community. Participants emphasized the need to improve functional ability and spoke about influential factors that drove the desire to improve post stroke life through participation in exercise. Participant stories identified influential factors for the *desire to improve post stroke life* including positive attitude, comparison of themselves before stroke and with others, awareness of health, and personal future goals. These influential factors for exercise participation supported plans to exercise to improve post stroke life, and are likened to ‘intention to exercise’ within the framework of exercise behaviour change. Participants did not describe these factors within the context of ‘intention’, as labeled in behaviour change models, but did identify them as motivators for their behaviour change and plan to engage in physical exercise to regain function following stroke.

Participants in this study spoke about exercise with a positive attitude secondary to the education and encouragement from HCPs. Participants’ positive attitude was linked to their encounters with HCPs who believed that exercise was beneficial to become ‘better’, even when exercise was not part of life for participants prior to stroke. Positive attitude was an early factor in the process of engaging in exercise when participants spoke about the *desire to improve post stroke life* and committing to exercise. The importance of addressing personal attitude of people living with stroke to influence intention for outdoor walking was highlighted previously in the work of Outermans et al. (2016). Behaviour change models, including TPB (Ajzen, 1985) and the PAD Model (van der Ploeg et al., 2004), recognized the influence of attitude on intention, which was seen as a precursor to behaviour (Rhodes & de Bruijn, 2013). This study described the impact of a positive attitude in participants to instil the intention to exercise, expressed as the *desire*

to improve post stroke life. This finding is supported by the PAD Model, which specifically recognizes attitude as a ‘personal factor’ influencing intention (van der Ploeg et al., 2004). The findings of this study provided insight into environmental factors, such as HCPs, as positive factors contributing to positive thoughts and feelings for exercise participation post stroke.

Desire to improve post stroke life as ‘intention’ was expressed through comparisons by participants to their previous self and others. Participants spoke about getting back to their *prestroke* lives. Previous work described a separation between *prestroke* and *poststroke* life secondary to the effects of stroke (Dowswell, et al., 2000; Reed, Harrington, Duggan, & Wood, 2010). Past literature reported that people living with stroke recognised and appreciated the positive effects of physical activity through comparison of themselves with stroke to their pre-stroke lives (Morris, Oliver, Kroll, Joice, & Williams, 2015). Participants in this study viewed exercise as a means of achieving their *prestroke* life and functional levels, or recovery from stroke.

Health awareness was achieved through self-reflection by participants after experiencing a stroke and contributed to ‘intention’ for exercise participation. Participants intended to be healthier to enhance their post stroke lives, where exercise was recognized as a means to improve health. The PAD Model suggests ‘health condition’ influences intention (van der Ploeg et al., 2004), but does not make specific reference to self-reflection on health as a mechanism. Awareness for health in study participants occurred with self-reflection on their new state of health living with the effects of stroke. Reflection was described in their health status prior to their stroke event, experiences of friends following health events, experiences of limited functional ability, and new knowledge gained from reading about stroke and recovery.

Personal goals influenced participants’ ‘intentions’ to exercise through the *desire to improve post stroke life*, which included physical functional improvement and maintenance, independence in day-to-day activities, and participating in things they enjoy. These findings resonate with previous literature describing the common goal

among survivors of stroke to achieve functional independence, as well as participate and become an active member in the community again (Hammel, Jones, Gossett, & Morgan, 2006; Kwakkel, Kollen, & Lindeman, 2004).

5.3 Navigating Exercise Opportunities

Over time participants navigated community exercise programs within the context of the daily challenges they faced from the effects of stroke on them as individuals. This phase in the process of exercise participation was interpreted as a ‘bridge’ between the *desire to improve post stroke life* or intention and *commitment to exercise* participation (i.e., behaviour). The findings of this study provided insight into the events that occurred as participants transitioned in behaviour change, and from intention to behaviour as represented in behaviour change models (Ajzen, 1985; van der ploeg et al., 2004). The PAD model (van der Ploeg et al., 2004) suggests some environmental and personal factors that may influence the well-known ‘intention-behaviour gap’ (Rhodes & de Bruijn, 2013; Sheeran & Webb, 2016; Sniehotta, Sholz, & Shwarzer, 2005), however, the PAD does not ‘label’ the transition. Findings of this study suggest ‘*navigating*’ describes the transition from intention to behaviour for participants. Navigation was used to describe the process when participants explored different types of exercise opportunities to achieve their desired outcomes from exercise participation. *Navigating* involved exploring exercise environments, programs and social opportunities to find an exercise environment to meet their needs for exercise participation. In some instances, participants reconnected with a familiar exercise facility or class from before their stroke, or searched for a new community program or exercise opportunity. Connecting and re-connecting to social exercise programs was important to foster the component of social relationships in commitment to exercise.

5.4 Commitment to Exercise

In the process of exercise participation for functional recovery following formal rehabilitation, participants described their commitment to exercise as part of their life. The findings of this study identified incentives for committing to exercise, including

social relationships, ability to overcome challenges to exercise participation, mastery of self-care skills, improved mobility, and recognition and pride in successes. As time progressed participants described a *commitment to exercise* that was fortified by positive physical (e.g., ‘mastery of self-care skills and improved mobility’ and ‘recognition and pride in successes’) and emotional changes (e.g., feeling ‘closer to self’ before the stroke and ‘ability to overcome [the daily] challenges to exercise’ participation from the effects of stroke).

Previous literature reported a lack of success for community services to meet the needs of individuals who had a stroke (Simpson, Eng, & Tawashy, 2011), and thus, potentially negatively impacted adherence to exercise programs by these individuals. Contrary to this statement, participants in this study sought out and actively engaged with community exercise services. A potential difference may be that participants in this study described the importance of belonging to a social group/interacting with others (environmental factor). Additionally, exercise participation with others nurtured other aspects of their lives, including returning to hobbies and leisure activities they enjoyed earlier in life. Further, participants described feelings of pride and mastery, and efforts to overcome challenges in everyday activities (personal factors) with exercise participation.

Commitment to exercise was positively reinforced through social relationships for the participants of this study. Previously, survivors of stroke indicated a challenge to maintain motivation in order to commit to exercise, where social support was recognized as helpful in ‘sustaining commitment’ (Poltawski et al., 2015). Social support, social interactions and social environment were expressed in other studies as motivating/facilitating exercise behaviour among individuals post stroke (Damush, Plue, Bakas, Schmid, & Williams, 2007; Nicholson et al., 2014; Outermans et al., 2016; Signal et al., 2016; Simpson et al., 2011). Findings of this study emphasized social connection as a facilitating factor to commitment, and further provided insight into the timing when this particular motivating factor was in play for people living with stroke. Research has noted the positive influence of individual beliefs/perceptions regarding cohesiveness of a group on exercise participation and adherence (Burke, Carron, & Shapcott, 2008; Estabrooks,

2000). The group setting has been successfully used as an agent of behaviour change (Burke et al., 2008; Estabrooks, 2000). It may be suggested that exercise adherence and commitment for participants of this study was influenced by group dynamics/interacting with others. Social aspects of exercise participation surfaced during ‘navigating’, and were described as a motivating factor in deciding which exercise program fit their needs. In developing and strengthening social relationships, participants felt a sense of belonging in a social group, which fostered their commitment to exercise participation. Participants described their commitment to exercise through the nurturing influences of being involved in a social group.

This study provides insight into challenges that survivors of stroke must overcome in committing to exercise and ideas for support systems by HCPs and community services. In committing to exercise, participants spoke about adapting exercises to their current level of ability by changing how they performed an exercise, or allowing for sufficient rest breaks and energy conservation to enhance their participation and outcomes from exercise. Some participants expressed overcoming challenges to exercise as they arranged for transportation, where poor transportation was previously recognized as an environmental barrier to exercise participation in the PAD model (van der Ploeg et al., 2004). Ongoing engagement in exercise was suggested to be influenced by the experience of success and identification of gains (Signal et al., 2016). The findings of this study align with this idea in that new ability and mastery of self-care skills provided participants with a feeling of pride in their successes, which reinforced exercise participation for continued improvement. Their achievements with exercise participation brought participants closer to their *pre-stroke selves*, a primary goal for many participants, positively reinforcing their commitment to exercise participation in the community.

5.5 Key Insights and Implications

Findings from this study contribute to understandings of exercise participation and may provide ideas for HCPs and community exercise programs to engage and support people living with the effects of stroke in exercise participation as part of an active lifestyle beyond formal rehabilitation services.

5.5.1 HCPs promoting positive patient-therapist relations and providing exercise education with sufficient patient understanding

The findings of this study are applicable to clinical practice. Participants spoke about how a positive initial exercise contact through a HCP initiated their success in exercise participation in the community, as well as influencing a positive attitude to promote continued exercise on their own. All participants in this study spoke about initial exercise contact with an HCP as essential to initiate the process of exercise participation for functional improvement and maintenance. As such, the initial exercise contact was essential for long-term exercise participation, health outcomes, and recovery. Therefore, time spent by HCPs in building rapport and a trusted relationship with people who have sustained a stroke may be critical for the long-term health, functioning and return to participation for people living with the effects of stroke.

Further, appropriate education and awareness provided by HCPs should address both cognitive and motor functional recovery following stroke. None of the participants in this study described the effects of cognitive impairment on functional recovery, raising concerns that the benefits of exercise on cognition may not have been part of the education provided by HCPs. Moreover, this missing aspect in the stories of study participants compared to the literature suggests that HCPs may need to play a more active role in addressing cognitive impairment through education about the role of cognition on recovery and participation for community living survivors of stroke.

5.5.2 Aligning goals and behaviour change with the *desire to improve post stroke life*

Participants of this study did not use the word ‘intention’ in their stories about continued exercise participation; rather, they described their intention for exercise behaviour as a *desire to improve post stroke life*, and noted several influential factors. This finding suggests that when applying health behaviour models, researchers and HCPs should remain open to hearing other ways of describing ‘intention’ that resonate with study participants/patients. Understandings of the term ‘intention’ and its encompassing factors may foster exercise participation, where exercise can be promoted specifically to the

descriptions of intention told by individuals. Reed and colleagues (2010) previously suggested that the effectiveness of goal setting is increased when goals are established within the context of an individual's life to promote meaning and relevance.

Additionally, as part of education about exercise, HCPs should emphasize components of exercise prescription that will guide individuals towards achieving their *prestroke* selves, as this was highly desired among the participants. Healthcare providers may need to include descriptions or examples of how exercise participation will link to and achieve the functional goals of the individuals. Examples may need to be explicit for understanding by people living with stroke and employed to increase uptake of exercise and exercise adherence in this population group.

5.5.3 Navigating to transition from intention to behaviour

The findings of this study suggest that '*navigating*' is a connecting bridge between *desire to improve post stroke life* (i.e. intention) and *commitment to exercise* (i.e. behaviour).

The findings address the gap in our understanding about the 'intention-behaviour' component of behaviour change models, specifically within the stroke population, where the transition from intention to behaviour may be described as *navigating*. It may be important for HCPs to understand of the process of navigation to guide patients towards exercise participation. Additionally, community services may benefit from understanding 'navigation' to attract individuals to their exercise programs.

5.5.4 Nurturing lifestyle in committing to exercise

In developing community exercise programs for people living with the effects of stroke, it may be important to consider implementing activities to enhance the lifestyle of the individuals, rather than having a sole focus on exercise classes. Previous research identified the act of HCPs acquiring knowledge of their patients' lives and personal interests as a potential influence on motivation in rehabilitation (MacLean, Pound, Wolfe, & Rudd, 2002). Participants of this study spoke about other aspects of their life that were nurtured (e.g., returning to painting, pleasure of reading) by belonging to the community

exercise program, which may have increased adherence rate in returning to the program and exercise. Perhaps these findings provide insight into the successes and failures of community exercise classes offered for people living with the effects of stroke in the community. It may indicate that community exercise programs have to go one step further to promote an overall lifestyle change, rather than a single component of change as seen through exercise recommendations and interventions.

5.6 Future Research

Given the significant influence of the initial exercise contact with an HCP, findings of this study allowed for exploration of continued exercise participation in survivors of stroke who perceived a positive interaction with the HCP. This raises questions about whether or not people living with the effects of stroke who did not perceive a positive initial exercise contact continued exercising for functional recovery. Future studies may be designed to understand the experience of people living with stroke who did not perceive a positive relationship with an HCP during the acute phase of their health condition. Given that *navigating* appeared to serve as a bridging component in the process of exercise participation for functional recovery, it may be beneficial to explore this idea further through a different lens and research approach, such as employing a focus group to elicit perceptions and provide detailed information and clarification about the process of *navigating*. The findings of this study revealed the idea of nurturing an individual's lifestyle as a component of exercise commitment, adherence and participation in the community. Future research may address the factors that facilitate success of community programs to promote adherence to exercise by people living with stroke in the community.

5.7 Limitations

In taking a constructivist grounded theory approach, findings of this study are co-constructions between the researchers and participants dependent on the context in which the interactions occurred. Therefore, findings must be understood within the specific

contexts and should not enforce absolute generalizations to the whole population of community living people recovering from the effects of stroke.

The inclusion criterion of ‘moderate’ exercise intensity was addressed through the definition of what was meaningful to participants and how they subjectively perceived their efforts during exercising (e.g., frequency during the week, becoming tired, sweating). No objective measures were implemented. The study may have benefited from objectively defining and measuring ‘moderate intensity’ (e.g., through rate of perceived exertion [RPE]) in order to interpret the findings within the parameters of participants’ experiences with moderate intensity exercise.

5.8 Conclusion

The process of continued exercise participation in the community for functional recovery among people living with the effects of stroke occurred in a series of phases. *Initial exercise contact* through a HCP was essential in commencing exercise post formal rehabilitation services. Following the initial exercise contact, survivors of stroke spoke about a *desire to improve post stroke life*, formulated by several factors. This desire was understood in terms of their intention to exercise. *Navigating* acted as a ‘bridging’ component in transferring their intention to *commitment to exercise* where commitment was fortified by positive physical and emotional changes. In committing to exercise, improvements in recovery were recognized, corresponding to an improved QOL. In addition to the four phases described within the process of exercise participation, this study contributed new knowledge to our understandings of exercise participation by people living with the effects of stroke. Findings suggested that the initial exercise contact with an HCP was critical to long-term exercise participation, health outcomes and recovery for people living with the effects of stroke, as exercise participation only commenced in the presence of an HCP. Findings provided knowledge and understandings regarding intentions to exercise, where ‘intention’ was described as the desire to improve post stroke life. Further, this study applied the term ‘navigating’ as part of exercise participation to understand the transference of intention to behaviour as per behaviour change models. Lastly, findings suggested that commitment to exercise was fortified by nurturing lifestyle change, or return to aspects of *prestroke* self. Insights from this study

may enable community health interventions, and timing of such interventions, along the continuum of recovery following stroke for fluid transitions during the process of exercise participation.

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Appendix A: Poster for Recruitment



PARTICIPANTS needed for RESEARCH about Exercise POST-STROKE

We are looking for individuals who have experienced a **stroke** and currently **exercise**

Exercise can help maintain or improve functional recovery post-stroke. **We need YOU** to tell us about your experience with exercise post-stroke.

Eligibility

- Men or women who have experienced a stroke
- You are currently exercising to maintain or improve function
- Your stroke didn't affect your ability to talk
- You are not a patient of rehabilitation
- You understand and speak English
- You are able to talk to us 1-2 times, for 1 hour each time

For more information about this study, please contact:
Nicole Evans



26/11/2017

Appendix B: Interview Guide

14/05/2017

Interview Guide

First Interview

1. Tell me about what exercise means to you.
2. How does exercise fit into your daily life? How does it benefit you?
3. What are your ideas about exercise?
 - What does exercise look like for you?
 - How do you act on your ideas about exercising?
 - How are you motivated?
 - How are you limited?
4. What happens when you face challenges to do your exercise?
 - How are you encouraged when you face these challenges?
5. Tell me about a time when you wanted to exercise, but you didn't. What happened?
6. Tell me about a time when you were unmotivated to exercise, but you still exercised anyway.
 - Why did you exercise?
7. How do you feel the community supports you to exercise?
8. Since your stroke, tell me about how your ideas about exercise have changed?

Second Interview

The second interview will be based on themes gathered from the first interview. The following is an example of what would be asked.

1. Tell me about what you've been doing for exercise since the last time I spoke with you.
 - Has anything about how you exercise changed?
2. Tell me about how you plan to keep exercising over the next couple months?
 - Over the year
 - As you grow older
3. Tell me about what exercise means to you?

Appendix C: Sample Transcript and Coding

N: Again, thank-you for participating! I'm going to start with – if you could tell me what exercise means to you? And the type of exercise you are doing right now?

P1: Okay. I lay a lot of the blame on my stroke to – you know, middle age, you start putting weight on and everything – so, I look to the exercise to start taking off that weight. And since the stroke, there are a lot of things that are still wrong. My leg doesn't work the same way. My fine motor skills are terrible. As you can hear, my voice – its changed a little bit. So there's a lot of things that are still wrong that I want to improve. I want to get back to the way I was. I don't think it's going to happen to tell you the truth, but I would really like to get back there.

N: Okay. And you see exercise as a way to get back...

P1: Oh yeah, definitely! Yeah, you gotta work the muscles, and yeah.

N: Okay. And you were saying your leg – what side was affected?

P1: The right side

Comment [1]: Aging is negative

Comment [2]: Unhealthy habits/appearance

Comment [3]: Managing perceived causes of the stroke through exercise

Comment [4]: Negative feelings and perceptions about oneself

Comment [5]: Functional impairments connected to stroke

Comment [6]: Wanting to get 'better', comparisons to the way she was before

Comment [7]: Yearning to return to previous identity

Comment [8]: Doubtful about full recovery, aspirations for full recovery

Comment [9]: Knowledge of exercise and movement to improve

Appendix D: Sample Memo

Memo – Insights into Participant One

Feelings after interview

I just finished my first interview for the study. The interview was completed at the participants' home. Upon first impression, the participant was extremely welcoming and appeared to be happy in my presence. I was surprised when the participant opened the door, seeing a woman of average height with no immediate **visible deficits**. It wasn't until I reached out my right hand to shake her right hand that I was reminded of **"invisible disabilities"** in the absence of movement presented through reduced strength and function.

Comment [1]: I was naïve to physical appearance following a stroke – perhaps this was secondary to my experiences throughout my physiotherapy placements for acute care and neuro-rehabilitation stroke services.

Comment [2]: This may impact others perceptions on ability to exercise

Initial thoughts during transcription and analysis of the interview

Exercise described in terms of a lack of individual enjoyment: I was rather shocked to learn that P1 "hates" to do exercise (**by herself**) and doesn't "feel that much better" after exercise", yet she continues to exercise 3-5x/wk. What is the driving force here?

Comment [3]: But does a social environment make you "love" exercise? Or do you always "hate exercise" but are motivated by others around you?

Comment [4]: This is going against the common statement and my personal recognitions that exercise makes you feel better. I need to understand more about exercising in the absence of 'feeling good'

Internal disappointment regarding health: the cause of stroke was **blamed on the** natural aging process and weight gain (exercise is now seen as a way to **shed 'extra' weight**). The resulting effects were described in terms of impaired motor function and 'something being **wrong**'. P1 expressed wanting to get back to the way she **previously** was.

Comment [5]: Perhaps the driving factor to exercise arises in her descriptions of 'blame', as a means to prevent 'future blame'

Comment [6]: Exercise behaviour was initially recognized in terms of overall health, rather than explicitly stroke specific

Comment [7]: Wanting to make things right again

Comment [8]: Getting back to old self – this needs to be explored in more detail (in what regard is *old self* 'measured' and recognized)?

Appendix E: Ethics Approval



Research Ethics

Western University Health Science Research Ethics Board HSREB Delegated Initial Approval Notice

Principal Investigator: Dr. Denise Connelly
Department & Institution: Health Sciences\Physical Therapy,Western University

Review Type: Delegated
HSREB File Number: 109354
Study Title: Exercise Behaviour for Functional Recovery in Individuals living Post-stroke within the Community: process from intention to behaviour

HSREB Initial Approval Date: August 15, 2017
HSREB Expiry Date: August 15, 2018

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Western University Protocol		2017/07/29
Recruitment Items	Poster	2017/07/08
Letter of Information & Consent		2017/07/29
Instruments	Interview Guide	2017/07/08

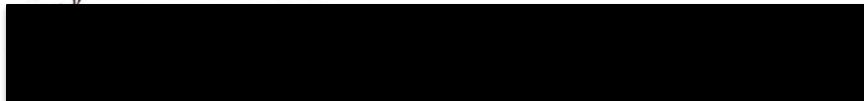
The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

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

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

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





Date: 8 January 2018

To: Denise Connelly

Project ID: 109354

Study Title: Exercise Behaviour for Functional Recovery in Individuals living Post-stroke within the Community: process from intention to behaviour

Application Type: HSREB Amendment Form

Review Type: Delegated

Full Board Reporting Date: 23/Jan/2018

Date Approval Issued: 08/Jan/2018 14:12

REB Approval Expiry Date: 15/Aug/2018

Dear Denise Connelly ,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Letter of Information and Consent Nov.26	Consent Form	26/Nov/2017	
Poster Nov.26	Recruitment Materials	26/Nov/2017	
Verbal Script	Recruitment Materials	18/Dec/2017	
Western Protocol Nov. 26	Protocol	26/Nov/2017	

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix F: Letter of Information and Consent



Project Title: Exercise Behaviour for Functional Recovery in Individuals living Post-stroke within the Community: process from intention to behaviour

Principal Investigator:

Dr. Denise Connelly, PhD, MSc, BScPT
Associate Professor, School of Physical Therapy
The University of Western Ontario

Co-Investigator:

Nicole Evans, BHK

Letter of Information

Invitation to Participate

You are invited to participate in a study about how people living in the community post stroke think about, plan and do exercise to maintain or improve functional recovery.

Purpose of the Letter

This letter describes a bit about the study and explains information so that you can make an honest and informed choice to participate or not.

Purpose of this Study

We know that exercise is a crucial component for functional recovery after a stroke. We know that during your recovery you have been exposed to exercise, doing exercises and/or education about the importance of exercise. During your recovery you've been supported to do exercise but the timeframe for your recovery continues after discharge to home. We don't know a lot about how individuals continue functional gains within the community. Therefore, we want to understand how individuals living in the community post-stroke continue and intend to exercise to maintain or improve functional recovery.

We would like to talk with you about how you think about, plan and do exercise in order to develop ideas about how health care providers and community services can support people living in the community post stroke to be active in exercise. We'd like to understand the types of things that motivate you, and that make it hard for you to exercise.

Who is eligible to participate?

We would like to talk with 10 people:

- men or women who have experienced a stroke
- who engage in exercise behavior at a moderate intensity
- who intend to exercise for the purpose of maintaining or improving functional capacity
- who are not a patient of rehabilitation

Who is not eligible to participate?

For this study, if you are experiencing difficulty speaking, or do not speak or understand English we are unable to include you.

Study Procedures

After you agree to participate in the study, we will schedule 1-2 interviews with you. Each interview will be approximately one hour in length. Where we meet you for the interviews is your choice. We can meet at your home, at Elborn College at Western University or another quiet place in your neighbourhood.

We record the interviews so that we can listen to them again and again, and we type them out so we can become very familiar with what our participants tell us. Agreeing to participate in the study means that you also agree that we can audio record the interviews with you.

Participant Rights and Confidentiality

Participating in this study is completely voluntary. You may refuse to answer any questions during the interviews, and may withdraw from the study at any time. If you choose to withdraw from the study, you have the right to request withdrawal of your information, unless the study has already been published. If you wish to withdraw from the study, please contact the co-investigator, Nicole Evans. Contact information is provided at the end of the letter.

The original audio recorded copy of the interviews is kept on a password protected computer in our office at the university. The audio recordings will be encrypted to prevent unauthorized access. When we listen and re-listen to your interview we do this only in the office at the university. When we type out the interview, we remove your name and any descriptions you use that may identify you. Identifying information is replaced with a unique study ID (i.e. "Bill" becomes "P1"). When we share your words in a research paper or a research presentation to make a point, we use the unidentified typed version. Your name

and email address/phone number are kept so we can contact you for a potential second interview. Your home address is collected in the event that you wish to have the interview at your home. This identifiable information is kept on a master list for the purpose of allowing the researchers to link participants to the unique study ID. The identifying information on the master list will not be revealed in the study process. The master list will be securely retained in a locked filing cabinet within a locked office at Western University. When the study is over we retain the information and audio recordings for 5 years as part of the Western protocol. The identifying information and audio recordings will be confidentially destroyed at 5 years. The unidentifiable transcripts may be kept indefinitely. If the results of the study are published, your name and personal information will not be used.

There is no compensation for participating in the study. If you do come to Elborn College for the interviews though we will arrange for free parking.

Representatives of The University of Western Ontario's Health Sciences Research Ethics Board may require access to your study-related records to monitor the conduct of the research.

You do not waive any legal rights by consenting to this study.

Risks and Benefits of Participating in the Study

You will be talking about how you plan, think about and do exercise, and the things that keep you going, make it harder and easier for you to exercise. Talking about these things may make you think about life prior to having a stroke. Thinking and talking about your life in this way may upset you emotionally. We will try to support you and answer any questions we can about exercise programs or information sources in the community that may help you.

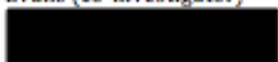
As well, as you talk and think you may gain some insights that will be meaningful and helpful to you. You may learn more about yourself and how to do exercise that may benefit you and assist with functional recovery post-stroke.

Contacts for Further Information

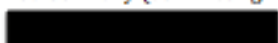
This letter is yours to keep.

If you have any questions or would like more information about the study or your participation in it, please contact:

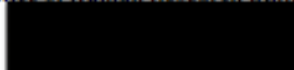
Nicole Evans (co-investigator)



Dr. Denise Connelly (co-investigator)



The Office of Human Research Ethics



Consent Form

Project Title: Exercise Behaviour for Functional Recovery in Individuals living Post-stroke within the Community: process from intention to behaviour

Principal Investigator:

Dr. Denise Connelly, PhD, MSc, BScPT
Associate Professor, School of Physical Therapy
The University of Western Ontario



Co-Investigator:

Nicole Evans, BHK



I have read the Letter of Information and understand the context of this study. I have had the study thoroughly explained to me with all questions answered to my satisfaction. I agree to participate in this study.

Participant's Name (Print): _____

Participant's Signature: _____

I provide consent for the researchers to use anonymous direct quotes from my interviews within the research Yes No

Date: _____

Researcher's Name (Print): _____

Researcher's Signature: _____

Date: _____

Curriculum Vitae

Name: Nicole Evans

Education: The University of Western Ontario – London, ON
Master of Health and Rehabilitation Science (Thesis)
August 2017 – Present

The University of Western Ontario – London, ON
Master of Physical Therapy
September 2015 – August 2017

The University of Windsor Ontario
Bachelor of Human Kinetics – Movement Science
September 2009 – April 2013

Related work experience: Physiotherapist
Eramosa Physiotherapy Associates – Acton
January 2018 – present

Physiotherapy Clinical Placement
University Hospital – London, ON
Acute care: inpatient neurology/neurosurgery
July – August 2017

Physiotherapy Clinical Placement
Hotel Dieu Grace Healthcare – Windsor, ON
Rehabilitation: inpatient neurology
November – December 2016