The Role of Community Exercise Programs Involving a Healthcare-Recreation Partnership for People with Neurological Conditions and their Caregivers

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science
Rehabilitation Sciences Institute
University of Toronto

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Abstract

Background: Group, task-oriented community-based exercise programs incorporating a healthcare-recreation partnership (CBEP-HRP) aim to enhance access to exercise participation for people with neurological conditions.

Objectives: 1) To explore the perceived impact of a group, task-oriented CBEP-HRP on physical function, participation, and caregiver assistance and health among people with neurological conditions and their caregivers, and 2) to understand their preferences for the content and timing of education about CBEP-HRPs.

Methods: A descriptive qualitative study involving in-depth interviews was conducted. A thematic analysis was performed.

Results: Two themes emerged suggesting exercise participants experienced interrelated improvements in body function, activities and participation that were reinforced through repeated registration in the program, and caregivers experienced both challenges and benefits associated with the TIME™ program.

Conclusions: Results provide directions for future research and program development, including incorporation of body function, activity, and participation as program outcomes and examining the need for exercise programs for caregivers.

Keywords: brain diseases, exercise, caregivers, qualitative, social participation
Acknowledgements

I would like to extend my sincerest appreciation to my primary thesis supervisor, Dr. Nancy Salbach. You have provided me with constant support, encouragement, and guidance. I have been very fortunate to have had you as my supervisor, and I will be eternally grateful. I would also like to thank my co-supervisor, Dr. Jill Cameron, for her expertise, invaluable feedback, and constant support. To my Program Advisory Committee, I would also like to thank Dr. Ruth Barclay for your interest, support, and insightful feedback in my research.

I would like to thank my friends and family for their continual support, love, and patience. Finally, I would like to thank the recreation providers, exercise participants and their caregivers who took time out of their busy schedules to assist with the study and share their valuable experiences with me.

This research was supported by an Ontario Physiotherapy Association Kim Wolny Research Grant and a Heart and Stroke Foundation Canadian Partnership for Stroke Recovery Catalyst Grant.
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ADLs: Activities of daily living
BI: Barthel Index
CAS: Caregiver Assistance Scale
CSI: Caregiver Strain Index
CBEP: Community-based exercise program
CBEP-HRP: Community-based exercise programs incorporating a healthcare-recreation partnership
CDSR: Cochrane Database of Systematic Reviews
CHAMPS: Community Health Activities Model Program for Seniors
CPAG: Canadian Physical Activity Guidelines
HCP: Healthcare professional
HRQL: Health-related quality of life
IADLs: Instrumental activities of daily living
ICF: International Classification of Functioning, Disability and Health
MS: Multiple sclerosis
PD: Parkinson’s disease
PT: Physical therapist
RCT: Randomized controlled trial
TIME™: Together In Movement and Exercise
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CHAPTER ONE

INTRODUCTION
1. Introduction

Neurological conditions are a primary cause of disability in Canada, resulting in impairment, activity limitation, and participation restriction.\textsuperscript{1} In Canada, stroke and multiple sclerosis (MS) are the most common neurological conditions.\textsuperscript{2,3} Specifically, stroke is the third leading cause of death and long-term disability,\textsuperscript{3-5} and results in an estimated cost to the Canadian economy, including physician services, hospital expenses, lost wages, and reduced productivity of $3.6 billion annually.\textsuperscript{6} A stroke results in the abrupt loss in brain function due to a disruption in blood supply to the brain or bleeding as a result of a ruptured artery.\textsuperscript{7} The impact of the stroke varies due to the complexity of the brain and the location and extent of the damage. Canada has one of the highest prevalence rates of MS in the world, a condition that affects young adults.\textsuperscript{8,9} The annual cost to the Canadian economy, including physician services, hospital expenses, medications, morbidity and mortality is nearly $950.5 million.\textsuperscript{3,10} The impact of MS on the individual varies due to the unpredictable demyelination throughout the central nervous system.\textsuperscript{3,11}

Neurological conditions result in similar impairments, leading to activity limitations and participation restrictions. Chronic balance and mobility limitations are common, contributing to low levels of physical activity, activity limitations, and participation restriction (social, occupational, and recreational).\textsuperscript{12-15} Moreover, not only do chronic balance and mobility limitations affect the individual, but they also affect family caregivers by contributing to burden or strain, in turn impacting caregiver health and well-being.\textsuperscript{16-19} A family caregiver is defined as an unpaid family member, friend, or neighbour who is most closely involved in helping the individual with a neurological condition to live independently at home and provide support and
assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs)\textsuperscript{20, 21} at least once a week.

Formal rehabilitation, although essential in helping individuals with neurological conditions relearn and regain lost skills,\textsuperscript{22-24} lasts for a limited period of time. Continuing opportunities or programs involving physical activity and exercise are needed to maintain or improve health once the individual is discharged to the community. Canadian Stroke Best Practice Recommendations\textsuperscript{25} state that it is best practice to provide individuals with information regarding community resources, such as community-based exercise programs (CBEPs), to enable a successful return to the community post stroke. Various types of CBEPs have shown to be beneficial for individuals with neurological conditions.\textsuperscript{26-32}

The following chapters of the thesis contain a literature review, followed by a scoping review and a qualitative study, and ending with a summary and conclusion. The purpose of the literature review was to provide an overview and analysis of the published literature, including a critical synthesis of the material pertaining to the epidemiology of neurological conditions, impairments, activity limitations and participation restrictions resulting from neurological conditions, caregiving in the context of neurological conditions, rehabilitation length of stay, importance of exercise and recommendations, barriers to engaging in exercise following discharge from rehabilitation into the community, effectiveness of different rehabilitation interventions, and CBEPs. This area of research is preliminary. It is uncertain whether there is a sufficient volume of research evaluating similar types of CBEPs on comparable and important outcomes in the same population to justify a systematic review. At this stage, a scoping review is appropriate to examine the range, nature, and extent of the literature, to determine the feasibility of conducting a systematic review, to summarize and distribute findings, and to identify gaps in
the current literature. Specifically, the purpose of the scoping review was to describe the extent, range and nature of the literature involving CBEPs delivered by fitness providers in people with neurological conditions, including the populations and outcomes studied, the presence of a partnership between fitness instructors and healthcare professionals (HCPs), and the study designs used, to identify gaps in the current literature and guide subsequent development and evaluations of CBEPs. The results of the scoping review provided a rationale for the objectives of the qualitative study, which aimed to explore the perceptions of individuals with neurological conditions and their caregivers of a group, task-oriented community-based exercise program incorporating a healthcare-recreation partnership model (CBEP-HRP) on physical function, participation, caregiver assistance and caregiver health, and to understand participants’ and caregivers’ preferences for the content and timing of education regarding CBEPs. The purpose of the final chapter was to provide a summary and conclusion of the thesis, including key considerations for future research.
CHAPTER TWO

LITERATURE REVIEW
2.1 Epidemiology of neurological conditions

The nervous system (brain and spinal cord) controls body functions and movements.33 Neurological conditions are disorders of the nervous system that may cause paralysis, weakened muscles, decreased coordination, loss of sensation, seizures, confusion, pain, and disrupted cognitive functions and communication (e.g., aphasia). In Canada, neurological conditions are a primary cause of disability resulting in individuals facing long-term challenges associated with decreased functioning and activity limitations.1 Common neurological diseases, disorders, and injuries identified by the Canadian Institute for Health Information include Alzheimer’s disease, amyotrophic lateral sclerosis, brain tumors, cerebral palsy, epilepsy, head injury, headaches, MS, Parkinson’s disease, spinal injuries, and stroke.2, 3

Stroke is the third leading cause of death and long-term disability in Canada.3-5 Stroke is an abrupt loss in brain function caused by either a disruption in blood supply to the brain (ischemic stroke) or bleeding into or around the brain as a result of a ruptured artery (intracerebral or subarachnoid hemorrhage). The majority of strokes (80%) are ischemic in nature.7, 34 The incidence of stroke in Canada is approximately 50,000 per year.4 In 2000, the annual cost of stroke to the Canadian economy, including physician services, hospital expenses, lost wages, and reduced productivity, was nearly $3.6 billion.6 In 2007, the annual cost of informal caregiving to survivors of stroke in Ontario alone was estimated at $150 million.35 Death as a result of stroke is more likely in women than men, however men have a higher lifetime risk of experiencing a stroke.3, 4 In individuals over the age of 55 years, the risk of stroke doubles every 10 years.4 Due to the brain’s complexity in controlling various body functions, the impact of stroke on an individual varies with the location and extent of the lesion.
Nevertheless, most survivors of stroke experience some degree of recovery, including recovery in motor function, sensation, and communication.\textsuperscript{36}

In young adults globally, MS is the most common disabling neurological condition,\textsuperscript{11, 37} with a typical age of onset between 20 to 50 years.\textsuperscript{3, 38} In Canada, approximately 93,500 individuals live with MS, which is one of the highest MS prevalence rates in the world.\textsuperscript{8, 9} MS is three times more common in women than men.\textsuperscript{3, 38} It is a disabling disease involving damage to the sheaths of nerve cells residing in the brain and spinal cord.\textsuperscript{11, 38, 39} There are two main types of MS, including relapsing-remitting MS (i.e., episodic relapses and remissions) and primary-progressive MS (i.e., steady and slow progression). Relapsing-remitting MS is the most commonly occurring type of MS (85\%).\textsuperscript{3, 11} The cost of MS to the Canadian economy in 2000-2001, including physician services, hospital expenses, medications, morbidity and mortality, was nearly $950.5 million annually.\textsuperscript{3, 10} Due to its unpredictability and the variable distribution of demyelination throughout the central nervous system, MS may affect various body functions and activities, including vision, audition, speech, memory, balance, coordination, strength, and mobility.

\textbf{2.2 Impairments related to neurological conditions}

Individuals with various neurological conditions, such as stroke and MS, have similar impairments leading to activity limitations (i.e., activities of daily living (ADLs) and instrumental activities of daily living (IADLs)) and participation restrictions. ADLs refer to basic self-care tasks of everyday life (i.e., eating, grooming, bathing, dressing, toileting, transferring).\textsuperscript{40} IADLs are complex skills required for successful independent living (i.e., transportation, shopping, meal preparation, housework).\textsuperscript{41} Specifically, chronic balance and mobility limitations
as a result of neurological conditions are commonly experienced and contribute to decreased levels of physical activity and participation in meaningful activities.12-15

2.3 International Classification of Functioning, Disability and Health (ICF) framework

The ICF framework42 was used to guide the scoping review and interpretation of the findings from the qualitative study. This framework was chosen as it was developed to describe the impact of a health condition on the individual and provides a universal language and framework for HCPs and researchers to use when describing health and health-related states.42 The framework classifies the health components of functioning and disability into four categories: body structure and function, activities and participation, environmental factors, and personal factors. The ICF42 components are defined below:

Body structure and function – “Functions are the physiological functions of body systems (including psychological functions). Structures are anatomical parts of the body such as organs, limbs, and their components. Impairments are problems in body function or structure such as a significant deviation or loss.” Examples include strength or motor function, and confidence.

Activity – “Execution of a task or action by an individual. Limitations are difficulties an individual may have in executing activities.” Examples include standing up from a chair, walking, ADLs and IADLs.

Participation – “Involvement in a life situation. Restrictions are problems an individual may experience in involvement in life situations.” Examples include participation in relationships, work, social, and leisure activities.
Environmental factors – “Make up the physical, social and attitudinal environment in which people live and conduct their lives.” Examples include the built environment (physical), and family caregiving (social).

Personal factors – “The particular background of an individual’s life and living, and comprise features of the individual that are not part of a health condition or health states.” Examples include age and culture.

The individual’s level of function in a single domain (i.e., body functions and structures, activities, and participation) is a dynamic interaction or multifaceted relationship between the health condition and contextual factors (i.e., personal and environmental). That is, interventions in one domain may affect one or more of the other domains.

2.4 Balance and mobility limitations post stroke

Stroke impacts the individual in various ways, including impairing motor function (decreased motor control, range of movement, or mobility limitation) and balance. Approximately 66% of individuals post stroke experience mobility deficits, with approximately 30% being unable to walk independently 6 months after. Nearly 83% of individuals with stroke experience balance impairment, which may result in an increased risk of falls and a reduced capacity for ADLs and mobility.

2.5 Balance and mobility limitations in individuals with multiple sclerosis

Balance and mobility are vital to physical functioning and the ability to perform ADLs in individuals with MS. Balance impairment is experienced by approximately 75% of individuals with MS, and is a significant risk factor for falls. It leads to difficulty in changing positions, maintaining a straight posture, and performing ADLs and functional activities, such as walking. Limitation in mobility is experienced in 93% of individuals with MS over time.
2.6 Balance and mobility limitations contribute to low levels of physical activity

In a study of older adults with one or more chronic diseases, only 23% met the recommended amount of leisure-time physical activity. Findings from a systematic review of literature describing physical activity post stroke indicated that reduced mobility, walking ability, aerobic fitness, balance, and increased depression were associated with low levels of physical activity. Results of a meta-analysis indicated that physical activity levels in individuals with MS were lower compared to non-diseased populations. Studies examining steps per day in individuals with neurological conditions, such as stroke and MS, reported only 4,355.2 and 5,903±3,185 steps per day, respectively. This is below the 7,000-10,000 steps per day recommended for healthy elderly populations over the age of 65 years and below the 6,500-8,500 steps per day recommended for people with disability and/or chronic conditions.

2.7 Activity limitation and participation restriction as a result of balance and mobility limitations

Individuals with chronic conditions experience activity limitation (e.g., ADLs and IADLs) and participation restriction in at least one meaningful role (e.g., social, occupational or recreational). Individuals with stroke require assistance in performing ADLs and IADLs for up to six years post stroke. Although people with stroke can independently perform select basic ADLs (i.e., eating) at one-year and six-years post stroke, the majority of individuals still require assistance with ADLs (i.e., dressing, toileting, grooming), and use of stairs. Moreover, individuals one-year and two-years post stroke have lower performance and an increased prevalence of activity limitation in IADLs than in basic ADLs. Individuals with stroke also experience participation restrictions in at least one meaningful role, whether it is social, occupational, or recreational. According to a study examining activity, participation, and
quality of life 6 months post stroke, 53% of individuals with stroke lacked meaningful activity (i.e., occupational, recreational, or social), potentially leading to decreased health, function, and quality of life.47 Another study on the long-term outcomes post stroke showed a high prevalence of participation restriction up to 4 years after stroke.60

As with stroke, individuals with MS exhibit activity limitations (i.e., ADLs, IADLs) and participation restrictions (i.e., social, occupational, and recreational).65-68 In one study on ADLs and social activities in individuals with MS, 52% of individuals with MS were independent in performing ADLs, 30% were independent in performing IADLs, and 35% participated in social or lifestyle activities, leaving nearly 66% of individuals with MS limited in their abilities to perform ADLs, IADLs, and participate in social, lifestyle, or occupational activities.68 Such activity limitations and participation restrictions result in poor outcomes, including decreased quality of life and well-being of individuals with MS.69-72

2.8 Who is a caregiver?

A family caregiver is defined as an unpaid family member, friend or neighbour who is most closely involved in helping the individual with a neurological condition to live independently at home and provide support and assistance with ADLs and IADLs20,21 at least once a week. Caregivers make an important contribution to rehabilitation, recovery, and ongoing care to individuals with disability. This role can have negative consequences, for example burden, that can affect their health and wellbeing.

2.8.1 Caregiver roles in rehabilitation and recovery post stroke or with ongoing care of other chronic conditions

Caregivers of individuals with various neurological conditions, such as stroke and MS, play numerous roles in rehabilitation and recovery and have varying responsibilities based on the
unique needs of the individual and their condition. Common responsibilities of caregiving may include physically assisting the individual with ADLs, IADLs, transportation, managing behavioural changes and providing emotional support, and coordinating healthcare appointments or medications.\textsuperscript{73,74} According to the “Timing It Right” framework for caregivers of stroke survivors, caregivers may experience 5 phases in which they may play various roles related to the time surrounding the event/diagnosis of the neurological condition, stabilization, preparation, implementation, and adaptation phases.\textsuperscript{75} In phase 1 (i.e., event/diagnosis), upon the sudden onset of the stroke, caregivers’ roles involve focusing on treatment options and whether the health event is life threatening. In phase 2 (stabilization), once the individuals’ condition has stabilized, the caregivers’ role involves seeking information from HCPs regarding the effects and impact of the stroke, as well as participating in the rehabilitation process with HCPs. In phase 3 (preparation), the caregivers’ roles include acquiring information and training from HCPs in assisting and providing care in the home setting, as the individual would soon be returning home. Moreover, caregivers may seek information regarding available community services. In phase 4 (implementation), the individual is able to return home. The caregiver is now responsible for providing most of the care needed by the individual (i.e., with ADLs and IADLs), and applying the skills they learned in the acute or rehabilitation setting to the home setting. Caregivers begin to develop routines, take over tasks the individual normally undertook, coordinate healthcare follow-ups, assist with transportation and mobility, and aid in secondary prevention. Furthermore, caregivers may seek out community services (e.g., exercise programs, community care, and support groups) as home care services (i.e., care provided in the home, including personal care, housework, meal preparation, and healthcare) may be restrictive. In phase 5 (adaptation), caregivers continue assisting in ADLs and IADLs and shift their focus towards
helping the individual reintegrate back into the community through participation in meaningful activities.  

The TIR framework may be applied to caregivers of individuals with MS (specifically relapse-remitting MS, as it is the most commonly experienced form of MS). Rehabilitation for individuals with MS involves evaluation and problem identification by HCPs, goal setting, rehabilitation treatments (i.e., interventions aimed at increasing functional capacity), and ongoing planning (i.e., adherence to programs initiated, reassessment and monitoring disease progress, interaction with community resources, and long-term planning). These aspects of the rehabilitation process for individuals with MS can be applied to the specific phases of the TIR framework, as caregivers of individuals with MS focus on the relapse events, prepare to care for the individual with MS through ongoing planning, implement the plans and adhere to the programs that have commenced, and adapt through long-term planning and engagement in community resources. There is a need for further research to consider or explore the various phases of care related to MS. Specifically, future studies are required in this area to understand the changing nature of caring for an individual with a relapse-remitting condition.

2.8.2 Caregiver burden (subjective and objective)

Caregivers are faced with the responsibility of providing care to the individual with a neurological condition, as well as making adjustments in their own life. As a result, caregivers experience burden or strain. Caregiver burden is defined as “the weight or load carried by caregivers as a result of adopting the caregiving role”. It can be divided into subjective and objective burden. Objective burden includes the physical and emotional assistance provided by caregivers. This comprises direct tasks of care (e.g., ADLs and supervision of the individual), indirect tasks of care (e.g., taking over household tasks that the individual normally
undertook, including IADLs and managing finances), and managing emotional needs of the individual (e.g., listening to the individual describe his/her distress and feelings, providing support and encouragement). Subjective burden includes the psychological, social, and emotional impact experienced by caregivers as a result of objective burden. This includes caregivers experiencing elevated psychological distress and depression, and interferences in other life roles (e.g., employment, and personal, financial, family interactions and routines, and social and leisure involvement).

2.8.3 Impact of caregiver burden on caregiver health and well-being

In a systematic review on caregiver burden following stroke, the prevalence of caregiver burden was 25-54% and continued to stay high for an indefinite amount of time post stroke. Poor caregiver mental health, longer duration of caregiving, and higher amounts of caregiving tasks performed (objective burden), are significantly associated with higher levels of subjective burden. Furthermore, caregivers may experience more burden when caring for disabled elderly individuals who have psychological and cognitive impairment as a result of a chronic disease. Another systematic review on the needs and experiences of caregivers of individuals with MS stated that caregivers reported poor quality of life, and this was associated with older caregiver age, low family income, caring for a spouse, increased duration and frequency of caring, increased severity of the individuals’ symptoms, and having an unstable disease course. Caregivers reported poor physical health, significant stress resulting in decreased psychological well-being, negative impact on their social life and financial strain.

2.9 Rehabilitation lasts for a short period of time

Rehabilitation is essential because it helps people with neurological conditions relearn and regain lost skills, as well as teaches them new ways of performing tasks to compensate for
any disabilities. However, inpatient rehabilitation lasts for a limited period of time. According to the Ontario stroke report, the median inpatient length of stay in rehabilitation was 28 days in 2011/2012. In Ontario, the median inpatient length of stay in rehabilitation for individuals with MS was 35 days in 2005/2006. Ongoing opportunities or programs involving physical activity and exercise are needed to maintain or improve health once formal rehabilitation is complete and the individual is discharged to the community.

2.10 Importance of exercise

Annually, approximately 3.2 million deaths are attributed to physical inactivity. A direct link exists between physical inactivity, decreased cardiovascular fitness and the occurrence of chronic conditions. Physical activity is defined as “any bodily movement produced by skeletal muscles that results in energy expenditure”. Exercise is defined as “a subset of physical activity that is planned, structured, and repetitive and has as a final or an intermediate objective the improvement or maintenance of physical activity”. Physical activity and exercise are beneficial for everyone, especially those affected by neurological conditions who are vulnerable to a sedentary lifestyle. For example, even moderate levels of physical activity, such as walking, can reduce the probability and severity of recurring stroke. Additional evidence suggests that increased physical activity results in improved cardiovascular health, reduced risk of cardiac events, enhanced physical fitness, improved balance and mobility, and lower levels of depression and social isolation in individuals with stroke. The importance of regular exercise is emphasized as a mechanism for maintaining health, as well as improving participation in meaningful roles, such as employment or social roles.

2.11 Physical activity recommendations

Participation in physical activity is important to healthy aging by preventing, improving, or slowing the progression of chronic diseases. The goals of physical activity and exercise
include enhancing balance, motor recovery or skills, muscle strength and endurance, exercise tolerance, walking speed and efficiency, independence in ADLs, competence in occupational activities, efficiency in recreational or leisure activities, and regaining levels of activity prior to the chronic condition.79

The Canadian Physical Activity Guidelines (CPAG) for older adults state that to attain health benefits, adults should spend at least 150 minutes per week performing moderate- to vigorous-intensity aerobic physical activity. In addition, the guideline recommends that people with physical disabilities should participate in balance, mobility and strength training programs at least twice a week.86 Stroke-specific practice recommendations suggest individuals participate in regular strengthening and aerobic exercise programs at home or in community programs designed for individuals with co-morbidities and activity limitations.87 These recommendations also suggest a frequency of ≥3 days per week of aerobic classes, with a 20-60 minutes per session, depending on the individual’s functional capacity, and can be broken down into multiple short sessions throughout the day.79 Moreover, task-oriented training has been recommended by the Canadian Best Practice Recommendations for Stroke Care.88 For people with MS, practice recommendations suggest engagement in 30 minutes of moderate-intensity aerobic activity twice a week. Strength training is also recommended for the major muscle groups twice a week.89

The Canadian Best Practice Recommendations for Stroke care90 promotes self-management skills (i.e., teaching individuals to take charge of their own health). A key component of self-management is exercise. This involves teaching individuals how to exercise independently, as well as the importance of exercise, especially following discharge from rehabilitation. Moreover, this involves linking these individuals to ongoing programs and resources to exercise in the community.
2.12 Challenges people with neurological conditions face engaging in exercise after discharge to the community

Individuals with neurological conditions face numerous barriers to participation in exercise following discharge to the community. A significant barrier is the lack of accessible and suitable CBEPs that are designed to meet the needs of people with physical disabilities.84

The built and natural environments are considered inaccessible for many reasons. A lack of curb cuts and inaccessible routes, narrow doorways restricting walker access, lack of elevators and ramps, and lack of handrails on stairs limit participation among individuals with disabilities in recreation programs or facilities.91 Cost and economic barriers include budgetary restraints in fitness facilities limiting their abilities to maintain or adapt exercise equipment for individuals with disabilities. It also prevents them from offering reduced memberships and providing transportation for individuals with disabilities.81,91 Equipment-related barriers, including a lack of space between equipment for walker access, poor equipment maintenance, and lack of adaptive or accessible equipment, limits use of community fitness centres for individuals with disabilities.91

Information-related barriers include recreation providers or fitness instructors having limited knowledge and expertise relating to individuals with disabilities, adapting programs and equipment to make it accessible for individuals with disabilities.91 Furthermore, information-related barriers include individuals with disabilities reporting a lack of knowledge and awareness regarding where to exercise in the community, recreation providers, the use of adaptive equipment, and what type or intensity of physical activity to perform.91,92

Individuals with disabilities may have uncertainties related to accessing fitness centres. These individuals fear the unknown, report having concerns about needing and requesting...
assistance, and state a lack of support from friends and family in accessing and participating in recreation programs.\textsuperscript{91} Moreover, individuals with stroke report feeling abandoned upon discharge from rehabilitation and rely greatly on family or friends for support. They are unable to drive and further rely on family or friends for transportation. As a result, this dependence can produce feelings of guilt which may prevent them from asking to be taken to extra activities such as exercise classes.\textsuperscript{93} Personal barriers such as a lack of motivation also contribute to participating less in physical activity.\textsuperscript{93}

2.13 Evidence of effectiveness of rehabilitation interventions delivered by rehabilitation professionals for community-dwelling people with neurological conditions

Evidence from randomized controlled trials, systematic reviews, and meta-analyses support the effectiveness of strength, aerobic, and task-oriented training in improving physical health in people with stroke and MS.

2.13.1 Benefits of progressive resistance strength training

Progressive resistance strength training consists of providing enough load (resistance) for the completion of a small number of successive repetitions before fatigue, and then gradually raising the amount of resistance as strength increases, therefore increasing the ability to endure and yield force.\textsuperscript{28} Results of systematic reviews on the outcomes of progressive resistance strength training in people with stroke, MS and Parkinson’s disease (PD) indicated that these training programs increased muscle strength,\textsuperscript{28-30} and improve functional ability.\textsuperscript{29} However, it is not known if strengthening enhanced participation in societal roles as no studies directly measured the effect of strength training on societal participation.\textsuperscript{28}

2.13.2 Benefits of aerobic training
Aerobic (cardiovascular) training consists of exercise performed for prolonged periods of time on ergometers (e.g., treadmill), or devices utilizing large muscle groups, or through activities such as walking, stair climbing, or cycling.\textsuperscript{27} Results of systematic reviews on the outcomes of aerobic training in people with stroke, MS and PD indicated that aerobic training may improve peak oxygen uptake and walking distance,\textsuperscript{27} manage fatigue,\textsuperscript{31} and improve motor action, walking, and balance.\textsuperscript{94}

2.13.3 Benefits of task-oriented training

Task-oriented training consists of repetitive practice of functional activities significant to an individual’s daily life including walking, reaching tasks for improving balance, sit-to-stand, and stairs.\textsuperscript{32} A systematic review evaluating task-oriented training in rehabilitation after stroke described improvements in functional outcomes of balance and mobility and overall health-related quality of life.\textsuperscript{32} Mobility is defined by the ICF as “\textit{moving by changing body position or location or by transferring from one place to another, by carrying, moving or manipulating objects, by walking, running or climbing, and by using various forms of transportation}.”\textsuperscript{42} Another systematic review evaluating task-oriented circuit class training on walking competency after stroke supported its use in improving walking and walking-related activities in patients with chronic stroke and indicated that task specificity and intensity of training are key factors associated with functional improvement.\textsuperscript{26}

These exercise modalities, such as resistance strength training exercises,\textsuperscript{28-30, 95} aerobic training,\textsuperscript{27, 96, 97} and task-oriented training\textsuperscript{26, 32, 98} are safe, feasible, beneficial and recommended for people with neurological conditions.\textsuperscript{86, 87, 99-101} However, these rehabilitation interventions have been commonly delivered by rehabilitation professionals who have clinical expertise working with people with neurological conditions. The decision to implement these interventions
as CBEPs should be guided by a number of factors, including the complexity of the intervention, space and equipment requirements, the level of expertise required by the instructor, and the risk of adverse events. Considering these factors, aerobic training may be challenging to implement for people with neurological conditions such as stroke, due to the need for ongoing monitoring (i.e., heart rate), need for modification to use specific equipment use (i.e., bikes) due to diminished lower extremity motor control, and possible increased muscle spasticity. Strength training may also be difficult to implement due to the potential for injury in loading joints of paretic muscles due to reduction in muscle strength. Therefore, although aerobic and strength training are beneficial when delivered in highly controlled experimental settings, task-oriented exercise interventions may be more feasible to implement in the community setting as they involve the practice of functional activities, such as standing up from a chair, that are applicable to everyday life.

2.14 Community-based exercise programs

A novel idea for addressing the barriers experienced by individuals with neurological conditions in engaging in physical activity and exercise in the community could be partially addressed through CBEPs. CBEPs have been developed from rehabilitation interventions and evidence of efficacy to address the need for available, accessible, and appropriate exercise programs for individuals with disabilities as a result of neurological conditions. CBEPs are defined as structured instructional programs of physical activity for groups or individuals delivered outside of a healthcare setting and available in community or recreation centres. Various types of exercise programs have shown to be safe, feasible, and beneficial for individuals with neurological conditions, including progressive resistance strength training, aerobic (cardiovascular) training, and task-oriented training.
2.14.1 Community-based exercise program incorporating a healthcare-recreation partnership model (CBEP-HRP)

An innovative model for increasing access to exercise programs in the community has emerged wherein HCPs with expertise in prescribing exercise for the target clinical populations (typically PTs) train and support fitness instructors to deliver exercise programs. This addresses the concerns regarding the ability of fitness instructors to implement CBEPs due to a lack of training and experience working with individuals with impaired motor control and complex comorbidity. Two examples of Canadian efforts to develop CBEPs include the “Together in Movement and Exercise” (TIME™) and NeuroFit programs described below. However, only the TIME™ program is a CBEP-HRP.

The TIME™ program is an example of a group, task-oriented CBEP-HRP. It targets improvement in balance and mobility and was modelled after exercise programs with evidence of efficacy in ambulatory individuals with stroke. The TIME™ program, as outlined in the TIME™ toolkit, consists of a one-hour group class, is offered to a maximum of 8 participants twice per week for a duration of 12 weeks. Each class is run by two fitness instructors to obtain the recommended ratio of 1 staff per 4 participants. The TIME™ program has been implemented in sites across Canada (i.e., Ontario and British Columbia). It is offered to a maximum of 8-16 participants either once or twice per week for 6-12 weeks. Each class is run by at least one fitness instructor and 1-2 volunteers to obtain the recommended ratio of 1 staff/volunteer per 4 participants. Fitness instructors are trained by PTs to deliver the program as outlined in the TIME™ toolkit. Classes involve a seated warm-up (10-15 minutes), cool-down (5-10 minutes), and exercises with varying levels of difficulty. Sites deliver the TIME™ program according to an earlier 9-station version (i.e., seated reaching, sit to stand & walk between chairs,
tap-up or standing & reaching, heel & toe raises or walking variations, standing weight shifts, dance steps, step-ups, aerobic station, arm range & motion\textsuperscript{109} or the modified 3-superstation version (i.e., superstation 1: walking, wall work, use of aerobic equipment; superstation 2: standing weight shifts, dance steps; and superstation 3: tap-ups, step-ups, heel and toe raises, hamstring curls, marching-on-the-spot, mini-squats).

The “NeuroFit”\textsuperscript{110} program is a 10-week CBEP, consisting of a one-hour class twice per week. The program includes two components designed by experienced PTs: 1) circuit training aspect in a small exercise area focusing on improving walking, balance and exercise tolerance; and 2) facilitated transition to standard gym equipment. The circuit training was adapted from previously developed programs (i.e., TIME\textsuperscript{92} and FAME\textsuperscript{111}). Exercises include a warm-up and ten stations focusing on improving 1) balance, 2) functional strengthening, 3) stepping, 4) seated reaching tasks, 5) standing reaching tasks, 6) cardiovascular training, 7) upper limb strengthening, 8) standing weight shifts, 9) walking variations, and 10) advanced dynamic balance.\textsuperscript{110} The transition aspect is tailored to each participant. Each station consists of 3 levels of difficulty. Upon mastering the levels, participants are transitioned to the open gym, where they are assigned an exercise partner (volunteer). With the aid of the PT, the participant and exercise partner work together in targeting, problem-solving and adapting to exercise equipment.\textsuperscript{110} The goal by the end of the ten weeks involves participants exercising in the gym using the equipment independently and sustaining activity levels.

2.15 Rationale for scoping review

The extent of the literature describing the CBEP-HRP model is unknown. A comprehensive review of CBEPs delivered by fitness providers in people with neurological conditions is lacking. A scoping review is needed to examine the range, nature, and extent of the
literature, to determine whether a systematic review is feasible, to summarize and disseminate findings, and to identify gaps in the current literature. Therefore, the topic of the next chapter is to provide an understanding of the extent, range and nature of the available literature involving CBEPs delivered by fitness providers in people with neurological conditions, including the presence of a partnership between fitness instructors and HCPs, the study design used, the populations and outcomes studied, as well as important outcomes such as cost of implementing the exercise program, healthcare utilization, and caregiver health. This would help to identify gaps in the current literature and guide subsequent development and evaluations of CBEPs."
CHAPTER THREE

Characterising Community Exercise Programmes Delivered by Recreation Providers for People with Neurological Conditions: A Scoping Review

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This manuscript was submitted for consideration for publication to the journal 

Health and Social Care in the Community Journal.

Note: This manuscript is in British English. Detailed descriptions of the methods used in the scoping review are presented beyond what would be expected in a manuscript submitted for publication
Abstract

Objective. To characterise evaluations of community-based exercise programmes (CBEPs) delivered by fitness instructors to people with neurological conditions.

Data Sources. A scoping review was conducted. Literature published from 1946 to April 2014 in MEDLINE, EMBASE, CINAHL, Cochrane Database of Systematic Reviews and the grey literature were searched. Search terms included community, programme, exercise, adult, brain disease, spinal cord disease.

Study Selection. Two reviewers independently screened titles and abstracts for inclusion. One author reviewed full-text articles to evaluate eligibility. Studies were included if the study objective was to evaluate an exercise programme, the programme was community-based and delivered by fitness instructors, exercise participants were ≥18 years of age and had a neurological condition, and a full-text article was available and written in English. After reviewing 1785 studies, 15 (0.84%) studies described in 18 articles were included in the review.

Data Abstraction. One author completed data abstraction from the included studies. A second reviewer independently verified the extracted data for accuracy.

Data Synthesis. Exercise programmes most commonly included people with stroke (47%) and Parkinson’s disease (40%), incorporated a stand-alone (80%), multi-component (20%), group (67%), individual (20%), and combined format (13%), strength training (60%) and aerobic training (53%), reported a minimum walking requirement (67%), and involved a healthcare professional with various roles (53%), including training (27%), advising and supporting (33%). The most commonly examined participant outcomes were health-related quality of life (60%), and functional balance (47%).
Conclusions. More research is needed to develop CBEPs targeting individuals with low ambulatory function and multiple neurological conditions, to develop recommendations for the involvement of healthcare professionals in CBEPs and document their involvement, and to evaluate system-level outcomes such as cost, healthcare utilization, and impact on caregivers. Findings support a number of considerations to guide future research on CBEPs delivered by fitness instructors for individuals with neurological conditions.

Key words: Brain diseases, spinal cord diseases, neurology, exercise, community
3.1 INTRODUCTION

Individuals with neurological conditions, such as stroke, Parkinson’s disease (PD), and MS, experience chronic balance and mobility limitations that contribute to low levels of physical activity. Nevertheless, individuals with neurological conditions wish to participate in physical activity because they view it as a beneficial and positive experience. However, they face numerous barriers to participation in physical activity. The built and natural environments are regarded as inaccessible. For example, the space between equipment in fitness centres is insufficient to enable use of ambulatory assistive devices. Cost-related barriers include membership and transportation costs, and budgetary restraints of fitness facilities to maintain or adapt exercise equipment for individuals with disabilities. Equipment-related barriers involve a lack of adaptive or accessible equipment in fitness centres. Information-related barriers relate to individuals with disabilities lacking knowledge of available and accessible exercise facilities and programmes in the community, recreation providers, the use of adaptive equipment, or the type and intensity of physical activity to perform. Moreover, fitness instructors have a lack of knowledge and expertise pertaining to individuals with disabilities, and a lack of knowledge regarding programme or equipment adaptation to make it accessible. Emotional and psychological barriers involve perceptions of persons with disabilities that recreation centres are unfriendly environments, with concerns about requesting assistance, and a lack of support from friends and family in accessing recreation programmes. The need to rely on family and friends for support causes feelings of guilt, which prevents individuals with disabilities from asking to be taken to extra activities such as exercise classes. Personal barriers such as a lack of motivation also contribute to lower rates of participation in physical activity.
Ongoing opportunities and programmes are needed to maintain or improve health once formal rehabilitation of individuals with neurological conditions is complete. Such programmes may be in the form of community-based exercise programmes (CBEPs) that we have defined as structured instructional programmes of physical activity for groups or individuals delivered outside of the healthcare setting and available in community or recreation centres. A number of exercise modalities, such as programmes involving resistance strength training exercises, aerobic training, and task-oriented training are safe, feasible, beneficial and recommended for people with neurological conditions. However, healthcare professionals (HCPs) have commonly led these programmes. There are concerns regarding the ability of fitness instructors to implement these programmes as they lack training and experience working with individuals with impaired motor control and complex comorbidity.

A healthcare-recreation partnership model for increasing access to exercise programmes in the community has emerged wherein physical therapists (PTs) train and support fitness instructors to deliver exercise programmes in recreation centres for people with neurological conditions. This model overcomes some of the barriers experienced by individuals with disabilities by increasing the knowledge and awareness fitness instructors have about people with disabilities as a result of neurological conditions and exercises pertaining to their needs through the training and support provided by knowledgeable and experienced HCPs. Moreover, this model helps to increase access to exercise programmes in the community for people with physical disability.

An understanding of the extent, range and nature of the literature involving CBEPs delivered by fitness providers in people with neurological conditions, including the populations and outcomes studied, the presence of a partnership between fitness instructors and HCP, and the
study design used, would help to identify gaps in the current literature and guide subsequent
development and evaluations of CBEPs. A comprehensive review of CBEPs delivered by
fitness providers in people with neurological conditions, however, is lacking. In one systematic
review, authors focused on randomized controlled trials (RCTs) of CBEPs as a strategy to
optimize function in chronic disease. The review targeted the top five chronic diseases which
included only one neurological condition (i.e., stroke). Of the three studies involving a stroke
population included in the review, only one study involved an evaluation of a CBEP
delivered by fitness instructors. This review also focused on functional capacity and health-
related quality of life (HRQL) as study outcomes. Thus, the nature and extent of available
literature evaluating the impact of CBEPs on important outcomes such as cost, healthcare
utilization, and caregiver health is unknown. The feasibility of conducting a systematic review is
questionable given the preliminary stage of this area of research. A scoping review is needed to
examine the range, nature, and extent of the literature, to determine whether a systematic review
is feasible, to summarise and disseminate findings, and to identify gaps in the current literature.

Therefore, the purpose of this study was to characterise the research and grey literature
describing evaluations of CBEPs delivered by fitness instructors in people with neurological
conditions. Specific objectives were to characterise the target populations, structure, content and
mode of delivery of exercise interventions, the involvement of the healthcare system in
interventions delivery, the research methodologies used, the study outcomes examined, and to
identify gaps in the literature.

3.2 METHODS

3.2.1 Study Design
A scoping review was conducted based on the five-stage methodological framework proposed by Arksey and O’Malley\textsuperscript{112} which included: 1) identifying the research question; 2) finding relevant studies; 3) selecting the studies; 4) abstracting data; and 5) analysing data (organising, summarising and recording the results).\textsuperscript{112, 113}

3.2.2 Finding Relevant Studies

Search strategies were developed with the aid of an information specialist with expertise in rehabilitation research. The scoping review searches were broad and focused on the central nervous system, specifically brain disease and spinal cord disease populations because the central nervous system is the main processing centre that plays an important role in many areas, including movement. When the central nervous system is affected, depending on the location and severity of the damage, individuals suffer long-term physical, cognitive, and psychological impairments. Moreover, by not limiting to specific neurological conditions, broad coverage of the literature can be ensured. The following bibliographic databases were searched from 1946 to April 2014: MEDLINE, EMBASE, CINAHL, and Cochrane Database of Systematic Reviews (CDSR). These large databases were chosen because they allow for the exploration of a broad range of literature, which is beneficial for a scoping review. MEDLINE was chosen over PubMed due to its ability to search more efficiently. EMBASE is the European equivalent of MEDLINE; it is a large biomedical database with less focus on North American content and more emphasis on European and Asian literature. CINAHL is another large database with a focus on nursing and allied health; as this scoping review explores community interventions, this falls under an allied health perspective. CDSR was used because this database is a leading resource for systematic reviews, which are considered the gold standard for evidence-based practice. Small and more specialized databases such as SPORTDiscus and AgeLine were not
included because they would be beneficial for systematic reviews, which are more targeted. Scopus, although a large database covering most of the health, life, physical and social sciences, was not included because of the considerable overlap between the articles in the database and MEDLINE and EMBASE. Search terms included: “community”, “programme”, “exercise”, “adult”, “brain disease” and “spinal cord disease”. Appendix A presents the full search strategy for MEDLINE. Reference Manager 12 software was used to import and sort the literature and remove duplicates. Subsequently, titles and abstracts were exported to Microsoft Excel to enable screening. The grey literature was searched using a tool provided by the Canadian Agency for Drugs and Technologies in Health. This tool consists of a comprehensive checklist of national and international websites organised by topic that can be searched using keywords. Lastly, reference lists of included articles and systematic reviews were examined.

3.2.3 Selecting the Studies

A form to screen titles and abstracts was developed in Microsoft Excel and pilot tested by two reviewers on the first 20 titles and abstracts. The reviewers discussed discrepancies and revised the form. Next, two reviewers independently reviewed the screening of titles and abstracts for inclusion. Upon completion of screening, reviewers compared results and resolved any differences through discussion. A third reviewer was consulted to resolve discrepancies. Next, a form was created to evaluate the eligibility of full-text articles and was pilot tested by two reviewers on the first five articles. Following pilot testing and revisions, one reviewer independently reviewed the rest of the full-text articles for inclusion in the scoping review.

Studies meeting the following inclusion criteria were considered eligible: 1) a study objective was to evaluate an exercise programme defined as a structured instructional programme of physical activity for groups or individuals to sustain or improve health or function
(stand-alone or multi-component programmes were included); 2) the exercise programme was delivered by fitness or activity-specific instructors (e.g., dance or boxing instructor); 3) the exercise programme was delivered in a non-medical community setting such as a municipal recreation centre, gym or church; 4) the study population was adults over the age of 18 years; 5) at least 75% of the study participants had a limitation in physical function (e.g., balance and mobility limitations) as a result of a neurological condition resulting in damage to the brain or spinal cord (as diagnosed by a physician); 6) the study was written in English; and 7) a full-text article or report describing the study was available online, or through the authors.

3.2.4 Abstracting Data

The PRISMA guideline for systematic reviews was followed as there is currently no scoping review guideline. The research team developed a form to abstract general study information (e.g., author(s), year of publication), study population, programme duration (in weeks), programme frequency (number of sessions per week), session duration (converted to hours), exercise components, setting (recreation providers), role and involvement of HCPs, study outcomes, the research methodology used to evaluate the exercise programme (study design, follow-up period, and data collection method), certification of fitness instructor, whether fitness instructors had experience working with individuals with disability, and whether exercise programmes were evidence-based (i.e., authors stated that the exercise programmes were evidence-based and referenced RCTs or guidelines). For RCTs included, abstraction of programme information was limited to the experimental intervention.

Two reviewers independently abstracted data from two articles to pilot test the form. They then met to review and discuss their responses. Subsequently, the form was revised. One reviewer then conducted data abstraction for the remaining articles. Once complete, a second
reviewer independently verified the extracted data for accuracy. The two reviewers met to discuss the results of the data abstraction and consulted a third reviewer to resolve discrepancies.

3.2.5 Data Analysis

Given the categorical nature of the data collected on all abstracted variables, findings were summarised using frequencies and percentages. Various occupational titles of exercise instructors (e.g., fitness instructor, personal trainer) were compared and categorised.

Study outcomes that were characteristics of the participant and caregiver were classified using the four components of the International Classification of Functioning, Disability and Health (ICF): 1) body structure and function (anatomical parts and physiological functions) or impairments (problems in body structure and function); 2) activities and participation (task execution and life situation involvement) or activity limitation and participation restriction; 3) personal factors (internal aspects of the individual’s background not part of their health condition or status, such as facilitators (i.e., attitudes) to participation in exercise programmes); and 4) environmental factors (enabling or hindering influences of the physical, social, and attitudinal world, such as barriers to participation in exercise programmes (i.e., transportation)). Safety was identified as a study outcome if authors provided results related to the safety of the exercise intervention regardless of whether they specified safety as a study outcome. Characterisation was conducted by listing each outcome, the outcome measure used, and ICF classification in a table. The ICF browser (http://apps.who.int/classifications/icfbrowser/) was used to verify the characterisation of each outcome within a specific ICF domain. Where classification was unclear, the measurement tool used for the specific outcome was examined. The classification table was verified for appropriateness by the co-authors, each with experience in using the ICF in research. Once characterisation was completed, the frequency and percentage of outcomes in
each ICF category were calculated. Non-ICF outcomes including participant HRQL, and exercise intervention characteristics, such as cost of implementing the exercise programme, safety and feasibility, where reported, were also recorded. Type of exercise and neurological condition were cross-tabulated to understand the range of exercise modalities evaluated in each condition. Table 3.1 lists the operational definitions for classifying the type of exercise and fitness or activity-specific instructors. Study outcomes using different terms were grouped. For example, outcomes describing quality of life, HRQL, health status, and well-being were classified as HRQL and outcomes describing physical and social integration, and community participation were classified as participation. Study outcomes for qualitative research were determined from the constructs listed in the study objectives. The time periods reported for follow-up evaluations were converted to time post-intervention to provide a common metric for comparison.

3.3 RESULTS

3.3.1 Study Selection

Of the 1785 titles and abstracts identified and screened, 18 articles representing 15 studies were included. Studies were conducted in the United Kingdom (n=6 studies; 40%; 9 articles), United States (n=5 studies; 33%), Australia (n=2 studies; 13%), Canada (n=1 study; 7%), and Italy (n=1 study; 7%) were included in the scoping review (Fig 3.1). No grey literature met the inclusion criteria. See Figure 3.1 for the process of study selection.

3.3.2 Research Methodology Used to Evaluate the Exercise Programme

The study designs utilized included RCTs (n=9 studies; 60%; 11 articles), a non-randomized before and after single group studies (n=2 studies; 13%), a non-randomized...
controlled trial (n=1 study; 7%), a time-series experimental design (n=1 study; 7%), a case series (n=1 study; 7%), and a qualitative study (n=1 study; 7%). The data collection method was quantitative only (n=10 studies; 67%; 11 articles), qualitative only (n=1 study; 7%), and both quantitative and qualitative (n=4 studies; 27%; 6 articles). Seven (47%) studies conducted follow-up evaluations after completion of the exercise intervention. These included an 8±2 week follow-up (n=1 study; 7%), 12- and 24-week follow-ups (n=1 study; 7%), a 3-month follow-up (n=3 studies; 20%; 5 articles), a 6-month follow-up (n=1 study; 7%), and 4- and 10-month follow-ups (n=1 study; 7%; 2 articles).

3.3.3 Target Populations

People with the following conditions participated in the reviewed studies: stroke (n=7 studies; 47%; 9 articles), PD (n=6 studies; 40%; 7 articles), traumatic or acquired brain injury (n=4 studies; 27%), MS (n=2 studies; 13%), cerebral palsy (n=1 study; 7%), degenerative cerebellar disease (n=1 study; 7%), motor neurone disease (n=1 study; 7%), myelopathy (n=1 study; 7%), neuromuscular disorders (n=1 study; 7%), transverse myelitis (n=1 study; 7%).

3.3.4 Eligibility Criteria for Acceptance into the Exercise Programmes

All studies reported programme eligibility criteria. Ten studies (67%) reported a minimum walking requirement including the ability to walk a minimum distance (range 3-20 metres) with or without the use of assistance or aid (n=4 studies; 27%; 5 articles), ambulatory (in the home setting) with or without the use of an assistive aid (n=3 studies; 20%), the ability to walk for six minutes (n=2 studies; 13%), and the ability to walk independently at a minimum speed of 1 meter/second (m/s) in a 10-meter walk test (n=1
Eight studies (53%) reported a minimum age requirement for acceptance into the programme, including 18 years (n=3 studies; 20%; 4 articles), 21 years (n=2 studies; 13%), 50 years (n=2 studies; 13%; 3 articles), and 40 years (n=1 study; 7%). Eight studies (53%) reported the minimum cognitive level requirement, which consisted of the ability to follow simple instructions, or maintain an exercise log. In three studies (20%), individuals with aphasia and dementia were not eligible for the programme. No studies reported use of criteria to exclude individuals at a high level of function.

3.3.5 Exercise Programmes (Structure, Content, Delivery)

Table 3.2 shows the structure and content of the exercise programmes including frequency of classes per week, duration of classes, and duration of programmes. Table 3.3 lists the type of exercise intervention evaluated by neurological condition. Exercise programmes consisted of individuals with a single neurological condition (n=13 studies; 87%; 15 articles) or with mixed neurological conditions (n=2 studies; 13%). Exercise interventions were delivered in gyms (n=8 studies; 53%; 9 articles), community or leisure centres (n=5 studies; 33%; 7 articles), a local shopping mall (n=1 study; 7%), and fitness centre (n=1 study; 7%). The exercise sessions were led by fitness professionals (n=14 studies; 93%; 17 articles), and dance instructors (n=1 study; 7%). The instructor to participant ratio, reported in five studies (33%), was 1:4 (n=2 studies; 13%; 3 articles), 1:6 (n=1 study; 7%), 1:6 or 1:3 (n=1 study; 7%), and 1:9 (n=1 study; 7%; 2 articles). In seven (47%) studies, authors reported the fitness instructors’ place of employment which was a not-for-profit recreation organization (n=6 studies; 40%), and a municipally-funded recreation provider (n=1 study; 7%). The charge for participating in the exercise programme, reported in three studies (20%),
was $3 per class (n=1 study; 7%), $5 per class (n=1 study; 7%), and $55 for the exercise programme session while participating in the study or $117 for the exercise programme session outside of the study (n=1 study; 7%). Five (33%) studies indicated that the exercise programme was evidence-based. The level of detail regarding fitness instructor qualifications varied across studies. Seven (47%) studies indicated that fitness instructors were certified. In 4 (27%) studies, the fitness instructor certification was specified (i.e., cardiopulmonary resuscitation, first aid, Can-Fit-Pro®, American Council on Exercise or American College of Sports Medicine certification, National Academy of Sports Medicine). Six (40%) studies did not provide any information on the fitness instructor qualifications. In 3 studies (20%; 4 articles), the fitness instructors had experience working with people with disability. Interventions of two studies included a home exercise programme or home exercise manuals.

### 3.3.6 Format of Exercise Programmes

Studies included stand-alone exercise programmes (n=12 studies; 80%; 13 articles) and multi-component programmes (n=3 studies; 20%; 5 articles) involving an exercise component and an education component. Exercise programmes were delivered in a group format (n= 10 studies; 67%; 11 articles), individual format (n=3 studies; 20%; 4 articles), and both group and individual format (n=2 studies; 13%; 3 articles).

### 3.3.7 Healthcare-Recreation Partnership Model

A HCP was involved in the exercise programme (n=8 studies; 53%; 10 articles). In each of these eight studies, the HCP was a PT. In four studies (27%; 5 articles), the PTs role was to train the fitness instructor in delivering the exercise programme.
In five studies (33%; 7 articles), the PTs’ role was to provide the fitness instructor and participants of the exercise programme with support and advice. In one study (7%), the PTs’ role was to determine the appropriate exercise for the participants of the exercise programme. In two studies (13%; 3 articles), the PT was involved in attending the first session. In one study (7%), the PTs’ role was to observe the exercise classes at random intervals throughout the exercise programme to ensure adherence to the exercise protocol. In one study (7%), the PTs’ role was to conduct initial visits to the exercise programme and provide input to instructors in teaching the exercises to participants. Details on the type of support, advice, and training by the PT were not provided.

3.3.8 Study Outcomes

Table 3.4 provides a classification of study outcomes for participants. For programme participants, studies evaluated outcomes classified as body structure and function (n=14 studies; 93%), activity (n=11 studies; 73%), and participation (n=7 studies; 47%). A caregiver outcome (strain) was examined in two studies (13%; 3 articles). Non-ICF outcomes included participant HRQL or QL (n=9 studies; 60%; 11 articles), and exercise intervention characteristics such as feasibility (adherence to exercise) (n=7 studies; 47%; 8 articles), safety (adverse events) (n=6 studies; 40%; 7 articles), appropriateness and acceptability of the programme (n=2 studies; 13%; 3 articles), healthcare system costs (n=1 study; 7%; 2 articles), social care costs (n=1 study; 7%; 2 articles), personal costs (n=1 study; 7%; 2 articles), and cost of implementing the exercise programme (n=1 study; 7%; 2 articles). No studies reported on participants continued engagement in exercise following completion of the exercise programme. Supplemental Table 3.1S provides a detailed description of each study.
3.4 DISCUSSION

This scoping review provides an overview of the nature and outcomes of research conducted to evaluate CBEPs delivered by fitness instructors for people with neurological conditions. The most common study designs utilized RCTs (4 studies in PD, 2 studies in stroke, and 2 studies in traumatic brain injury, and 1 study in PD, cerebral palsy, MS, motor neurone disease, neuromuscular disorders, traumatic brain injury, and transverse myelitis). The most commonly studied populations were stroke and PD. Of the programmes studied, classes were commonly one hour in duration, offered twice a week, with a programme length of 12 weeks, and involved strength and aerobic training. All programmes were delivered by fitness or activity-specific instructors. In over half of the studies, the exercise programmes involved a PT whose main roles were to provide training, support and advice to the fitness instructor. The most common data collection method was quantitative. The most commonly examined participant outcomes were HRQL and balance.

3.4.1 Type of Populations Evaluated

Findings from this scoping review indicate that little is known about the effects of CBEPs delivered by fitness instructors in people with neurological conditions other than stroke and PD. No studies were conducted in people with spinal cord injury, which has an annual economic burden of $2.67 billion for traumatic spinal cord injury in Canada. Further studies are needed to provide evidence of the effectiveness of CBEPs delivered by fitness instructors in single neurological condition populations to help justify the need for wide-scale implementation of CBEPs. People with various neurological conditions share similar activity limitations and participation restrictions. Therefore, CBEPs targeting functional level rather than diagnosis may be ultimately a preferred model, so that individuals with different neurological conditions can
participate in the same programme. Furthermore, there is a need for future studies to be conducted in different countries, such as Australia, Canada and Italy, as implementation challenges may differ across countries due to variable healthcare models, funding, culture, and built environments.

### 3.4.2 Structure, Content and Delivery of the Exercise Programmes

Exercise programmes were commonly delivered in a group format. Group exercise programmes enable social support, and increase confidence and self-efficacy.\textsuperscript{142} The majority of the studies involved strength training or aerobic training. In the RCTs included in this review, most of the exercise interventions were offered 2 or 3 times per week for one hour per class. According to systematic reviews for task-oriented walking and aerobic training, efficacious exercise interventions were frequently provided at least two classes per week.\textsuperscript{26, 27, 32} This amount of exercise helps the individual with a neurological condition work towards accumulating the recommended physical activity levels of 150 minutes of moderate- to vigorous-intensity aerobic training per week and strength training twice per week.\textsuperscript{86, 99-101} Furthermore, lifelong exercise participation is the goal. Repeated registration or engagement over time in various exercise programmes may be ideal for the individual with a neurological condition to maintain or improve their health.

Surprisingly, the instructor-to-participant ratio was not reported in more than half of the studies. This information is important to judging whether a programme is safe. In CBEPs involving balance and walking exercises, suggested instructor to participant supervision ratios range from 1:3 to 1:5.\textsuperscript{109, 111, 143} However, this may produce potentially higher costs of running these exercise programmes. Only one study evaluated the cost of implementing the exercise programme.\textsuperscript{121} Cost is a key consideration to determine what resources are involved in delivering
the exercise programme to replicate it elsewhere and to guide how to best implement the exercise programme based on the available funding. Moreover, no studies evaluated the impact of the CBEP on falls occurrence and only one study\textsuperscript{121} assessed impact on the cost of use of healthcare and social services and costs to the individual of attending the programme. Fall incidence and severity (i.e., level of injury) is associated with increased healthcare costs and thus the role of CBEPs in mitigating falls risk is worth examining.\textsuperscript{144}

The involvement of HCPs in CBEPs delivered by fitness instructors is important to ensuring the number, type and difficulty of prescribed exercises is appropriate for individuals with disabilities. Involvement of a HCP has the potential to increase the credibility of the programme by making individuals with disability feel safe.\textsuperscript{114} Just over half the studies involved PTs, which was expected because of their expertise in the physical rehabilitation of people with balance and mobility limitations resulting from chronic neurological conditions.\textsuperscript{43} PTs fulfilled a variety of roles related to education, training, and exercise prescription. The lack of detailed descriptions about roles limits the ability to replicate the studies or programmes and determine the resources needed. Furthermore, only one study involved the PT observing the exercise classes at random intervals during the programme. Ongoing collaboration between the PT and fitness instructor can help ensure the safe and appropriate delivery of the exercise programme to minimize adverse events, solve implementation issues, and optimize exercise benefits. Education and training toolkits\textsuperscript{109} and accreditation programmes\textsuperscript{145} are additional strategies for maintaining the quality and safety of the exercise programme.\textsuperscript{109, 145} Moreover, the United Kingdom has developed standards for the delivery of exercise for individuals post-stroke.\textsuperscript{146} An evidence-based accreditation course has also been designed involving Level 4 training for fitness instructors to design and deliver exercise programmes for the stroke population.\textsuperscript{146, 147} The
studies included in this review varied in the level of detail presented regarding fitness instructor accreditation, with only a few studies stating the specific certification.92, 137

Participants in the exercise programmes tended to be ambulatory and to have minimum cognitive deficits. Therefore, there is a lack of research evaluating CBEPs in people with other levels of physical and cognitive ability. However, CBEPs for people with more severe deficits would require extensive resources, such as greater involvement of HCPs to train and monitor for safety, more intensive training of fitness instructors on how to physically assist these individuals, and a lower instructor to participant ratio. Moreover, no studies reported a maximum programme eligibility criterion. It is useful to report both the minimum and maximum exercise programme admission requirements to more clearly define the population targeted by the programme and to facilitate replication and implementation of the CBEP.

A range of exercise programmes are needed; however there are certain types of exercises that are especially helpful to individuals with specific neurological conditions. Aerobic training, although beneficial, does not target balance impairments commonly experienced by individuals with neurological conditions, which can result in falls causing hip fracture and high hospitalization costs.148, 149 Approximately 83% of individuals with stroke44 and 75% of individuals with MS51 are affected by balance impairment; 50% of individuals with PD experience at least one fall due to imbalance.150 Task-oriented training is an important mode of exercise to implement in the community setting, as it involves the practice of functional activities that are applicable to everyday life.26, 32 Research on task-oriented training has shown to improve balance following repetitive practice of functionally relevant tasks, such as sit-to-stand or step-ups.32 Three studies evaluated non-traditional exercise programmes such as boxing training135, 136 and a tango dance programme,138 both for individuals with PD. Preliminary evidence suggests
that both boxing training and Argentine tango may be effective in improving balance, mobility, walking endurance, movement initiation and control, ADL, and quality of life in individuals with PD.\textsuperscript{135, 136, 138} These non-traditional exercise programmes relate to the guideline recommendations for PD, however they may be modified for individuals with other neurological conditions. Non-traditional exercise programmes provide creative alternatives to facilitate participation in physical activity for individuals with varying interests.

\textit{3.4.3 Research Methodology}

Most of the studies included in the review were RCTs. Due to heterogeneity in the clinical population, type of exercise intervention, and study outcomes, however, a systematic review or meta-analysis of the literature in an individual neurological condition would be premature. Additional RCTs are required to increase the body of research that would be appropriate for a systematic review or meta-analysis. Moreover, mixed methods were used in relatively few studies. Qualitative research methodology can be used to obtain an in-depth understanding of a phenomenon.\textsuperscript{151} Mixed method studies involving qualitative and quantitative data collection may be beneficial to better understand the processes behind observed quantitative results and to understand the exercise programmes and their effects through experiences and perspectives of participants.

\textit{3.4.4 Outcomes Characterised}

The examination of study outcomes revealed a number of gaps that may guide future research. Over half of the studies examined HRQL. HRQL is a main concern of HCPs and individuals with disabilities as a result of a neurological condition and involves assessing an individual’s well-being, including physical and mental health perceptions, which may be affected by disease or disability over time.\textsuperscript{152} Few studies assessed walking or mobility, which are
commonly limited by neurological conditions. Approximately half of studies examined balance and few studies examined activities of daily living (ADLs), which are essential considering many individuals with neurological conditions are affected by balance and upper limb motor impairment\textsuperscript{44, 51, 150} that impact their ADL. Few studies examined participation, physical activity and community reintegration, and no studies examined long-term engagement in exercise following completion of exercise programmes. Physical activity is important due to the multiple health benefits, such as reducing the risk of chronic disease and premature death, maintaining functional independence, mobility, muscle and bone health, mental health, improving fitness, and improving or maintaining body weight.\textsuperscript{86, 99-101} Moreover, CBEPs delivered by fitness instructors may help individuals with neurological conditions stay active by increasing their physical fitness, energy levels, strength, and mobility. Furthermore, results from the literature indicate that fitness instructors empowered participants, thereby increasing confidence in their abilities to perform various exercises, and improving attendance and ongoing engagement in exercise programmes.\textsuperscript{153} Additionally, exercises offered in a group and community setting may be beneficial to adherence as improvements were seen in engagement in exercise, benefits of exercise, and self-efficacy.\textsuperscript{154} Participating in CBEPs may enhance individuals’ reintegration back into the community and engagement or participation in meaningful life activities, such as occupation, relationships, or leisure activities.\textsuperscript{155} Therefore, the participation domain of the ICF needs to be studied further.

Additionally, individuals with neurological conditions want their caregivers to maintain good health and have a good relationship. Findings from the literature indicate that caregivers experience strain when their loved one has a physical disability.\textsuperscript{17, 156-158} Caregiver burden may be lessened if individuals improve in their ADL ability through CBEPs.\textsuperscript{92} However, caregiver
burden was examined quantitatively in only two studies.84,121 There is a lack of research examining how caregivers are influenced by participation of individuals with neurological conditions in CBEPs, including caregiver assistance and health.

3.4.5 Considerations to Guide Future Research

Findings from this review support a number of considerations to guide future research on CBEPs delivered by fitness instructors for individuals with neurological conditions. First, there is a need to target neurological populations in addition to stroke and PD. Second, there is a need to evaluate CBEPs among people with different levels of ambulatory ability. Third, there is a need to evaluate CBEPs involving task-oriented training owing to evidence supporting the benefit to balance and feasibility of implementing of this type of training. Fourth, there is a need to evaluate study outcomes at the ICF levels of activities and participation, system-level outcomes such as cost, and healthcare utilization, impact on caregivers, and long-term engagement in physical activity or exercise programmes. Fifth, there is a need to evaluate the extent and involvement of HCP and to better document this involvement to enable comparison across studies. Sixth, there is a need to evaluate CBEPs using a combination of quantitative and qualitative methodologies as CBEPs are complex multi-component interventions.

3.5 STUDY LIMITATIONS

This study has a few limitations. Firstly, in the Arksey and O’Malley112 framework, an optional sixth step is consulting with stakeholders to increase the value of the literature review. This step was not feasible to complete, however, due to limited resources. Secondly, this review included articles in the English language only.

3.6 CONCLUSIONS
This is an emerging area of literature as the scoping review was open to all neurological conditions and only a small number of studies were identified. Findings highlight areas for future research and provide guidance with respect to study design, population, data collection methods, exercise programme design, and outcomes for the evaluation of community-based exercise programmes in people with neurological conditions.

3.7 ACKNOWLEDGEMENTS

Saira Merali was supported by a Heart and Stroke Foundation Canadian Partnership for Stroke Recovery grant. Nancy Salbach and Jill Cameron were supported by Canadian Institutes of Health Research New Investigator and Ontario Ministry of Research and Innovation Early Researcher Awards. Ruth Barclay was supported by a Manitoba Health Council Establishment Grant.
Table 3.1. Operational definitions to classify the type of exercise or fitness professional

<table>
<thead>
<tr>
<th>Mode of exercise</th>
<th>Operational Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aerobic training</td>
<td>Described by authors as aerobic, cardiovascular, endurance or fitness training</td>
</tr>
<tr>
<td>Balance</td>
<td>Described by authors as performance of balance or agility exercises</td>
</tr>
<tr>
<td>Flexibility</td>
<td>Described by authors as performance of stretching or flexibility exercises</td>
</tr>
<tr>
<td>Strength training</td>
<td>Described by authors as strength or resistive exercise training</td>
</tr>
<tr>
<td>Task-oriented training</td>
<td>An exercise was classified as task-oriented training if authors described it as practice of “function” or a functional activity (e.g., walking, sit-to-stand, etc.) and evaluated physical function or performance of that activity, respectively, as a study outcome</td>
</tr>
<tr>
<td>Fitness or activity-specific instructors</td>
<td>Individuals who delivered the exercise interventions with various occupational titles as described by authors were compared and categorised as fitness professionals: certified personal trainer, personal trainer, fitness professional, qualified local exercise instructor, certified athletic trainer, gym staff, accredited fitness trainer, gym instructor, fitness instructor, trained instructor</td>
</tr>
<tr>
<td></td>
<td>Activity specific instructors included dance or boxing instructors</td>
</tr>
</tbody>
</table>
Table 3.2. Structure of exercise programmes

<table>
<thead>
<tr>
<th>Programme Characteristic</th>
<th>Number of Studies (%)</th>
<th>Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of Classes/Week</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>2 (13)</td>
<td>Hoffman et al. 2010, Kilbride et al. 2013/Norris et al. 2013</td>
</tr>
<tr>
<td>2 (every other week)</td>
<td>1 (7)</td>
<td>Poliakoff et al. 2013</td>
</tr>
<tr>
<td>2 or 3</td>
<td>2 (13)</td>
<td>Combs et al. 2011, Combs et al. 2013</td>
</tr>
<tr>
<td>Not reported</td>
<td>1 (7)</td>
<td>Wiles et al. 2008</td>
</tr>
<tr>
<td><strong>Duration of Class (hours)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 or 1.5</td>
<td>1 (7)</td>
<td>Cramp et al. 2010</td>
</tr>
<tr>
<td>1.5</td>
<td>3 (20)</td>
<td>Combs et al. 2011, Combs et al. 2013, Kilbride et al. 2013/Norris et al. 2013</td>
</tr>
<tr>
<td><strong>Duration of Programme (weeks)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>1 (7)</td>
<td>Harrington et al. 2010/Reed et al. 2009</td>
</tr>
<tr>
<td>10</td>
<td>2 (13)</td>
<td>Sims et al. 2009, Hoffman et al. 2010</td>
</tr>
<tr>
<td>14</td>
<td>1 (7)</td>
<td>Cramp et al. 2010</td>
</tr>
<tr>
<td>20 (every other week)</td>
<td>1 (7)</td>
<td>Poliakoff et al. 2013</td>
</tr>
<tr>
<td>24</td>
<td>1 (7)</td>
<td>Stuart et al. 2009</td>
</tr>
<tr>
<td>52</td>
<td>1 (7)</td>
<td>Foster et al. 2013</td>
</tr>
<tr>
<td>104</td>
<td>1 (7)</td>
<td>Corcos et al. 2013</td>
</tr>
<tr>
<td>Not reported</td>
<td>1 (7)</td>
<td>Wiles et al. 2008</td>
</tr>
</tbody>
</table>

Note: most frequently occurring result is bolded.
Table 3.3. Type of exercise intervention evaluated by neurological condition

<table>
<thead>
<tr>
<th>Type of Exercise Intervention</th>
<th>No. of Studies (%)</th>
<th>Condition</th>
<th>No. of Studies (%)</th>
<th>Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Stroke</td>
<td>4 (27)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Traumatic brain injury</td>
<td>2 (13)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cerebral palsy</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Motor neurone disease</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Multiple sclerosis</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Neuromuscular disorders</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Transverse myelitis</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stroke</td>
<td>3 (20)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Traumatic brain injury</td>
<td>2 (13)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cerebral palsy</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Motor neurone disease</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Multiple sclerosis</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Neuromuscular disorders</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Transverse myelitis</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Acquired brain injury</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Degenerative cerebellar disease</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Multiple sclerosis</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Myelopathy</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Parkinson’s disease</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stroke</td>
<td>2 (13)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cerebral palsy</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Multiple sclerosis</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Motor neurone disease</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Neuromuscular disorders</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Traumatic brain injury</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Transverse myelitis</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td><strong>Agility or coordination</strong></td>
<td>2 (13)</td>
<td>Parkinson’s disease</td>
<td>1 (7)</td>
<td>Kilbride et al. 2013/Norris et al. 2013, Poliakoff et al. 2013</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stroke</td>
<td>1 (7)</td>
<td></td>
</tr>
<tr>
<td><strong>Boxing</strong></td>
<td>2 (13)</td>
<td>Parkinson’s disease</td>
<td>2 (13)</td>
<td>Combs et al. 2011, Combs et al. 2013</td>
</tr>
<tr>
<td><strong>Dancing</strong></td>
<td>1 (7)</td>
<td>Parkinson’s disease</td>
<td>1 (7)</td>
<td>Foster et al. 2013</td>
</tr>
<tr>
<td><strong>NR</strong></td>
<td>1 (7)</td>
<td>Stroke</td>
<td>1 (7)</td>
<td>Wiles et al. 2008</td>
</tr>
</tbody>
</table>
Abbreviation: No., number.
Table 3.4. Classification of study outcomes

<table>
<thead>
<tr>
<th>ICF Category</th>
<th>Study Outcome</th>
<th>No. (%) of Studies with Outcome</th>
<th>Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Balance (postural control)</td>
<td>1 (7)</td>
<td>Kilbride et al. 2013/Norris et al. 2013</td>
</tr>
<tr>
<td></td>
<td>Cadence</td>
<td>1 (7)</td>
<td>Combs et al. 2011</td>
</tr>
<tr>
<td></td>
<td>Cardiovascular fitness</td>
<td>1 (7)</td>
<td>Hassett et al. 2009</td>
</tr>
<tr>
<td></td>
<td>Coordination</td>
<td>1 (7)</td>
<td>Poliakoff et al. 2013</td>
</tr>
<tr>
<td></td>
<td>Glucose tolerance</td>
<td>1 (7)</td>
<td>Stuart et al. 2009</td>
</tr>
<tr>
<td></td>
<td>Head injury symptoms</td>
<td>1 (7)</td>
<td>Hoffman et al. 2010</td>
</tr>
<tr>
<td></td>
<td>Locus of control</td>
<td>1 (7)</td>
<td>Sims et al. 2009</td>
</tr>
<tr>
<td></td>
<td>Movement speed</td>
<td>1 (7)</td>
<td>Corcos et al. 2013</td>
</tr>
<tr>
<td></td>
<td>Muscle power</td>
<td>1 (7)</td>
<td>Elsworth et al. 2011/Winward et al. 2012</td>
</tr>
<tr>
<td></td>
<td>Muscle tone</td>
<td>1 (7)</td>
<td>Cramp et al. 2010</td>
</tr>
<tr>
<td></td>
<td>Optimism</td>
<td>1 (7)</td>
<td>Sims et al. 2009</td>
</tr>
<tr>
<td></td>
<td>Pain</td>
<td>1 (7)</td>
<td>Hoffman et al. 2010</td>
</tr>
<tr>
<td></td>
<td>Perceived exertion</td>
<td>1 (7)</td>
<td>Poliakoff et al. 2013</td>
</tr>
<tr>
<td></td>
<td>Reaction time</td>
<td>1 (7)</td>
<td>Poliakoff et al. 2013</td>
</tr>
<tr>
<td></td>
<td>Self-esteem</td>
<td>1 (7)</td>
<td>Sims et al. 2009</td>
</tr>
<tr>
<td>Sleep</td>
<td>1 (7)</td>
<td>Hoffman et al. 2010</td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td>-------</td>
<td>---------------------</td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>1 (7)</td>
<td>Hassett et al. 2009</td>
<td></td>
</tr>
<tr>
<td>Step width</td>
<td>1 (7)</td>
<td>Combs et al. 2011</td>
<td></td>
</tr>
<tr>
<td>Stride length</td>
<td>1 (7)</td>
<td>Combs et al. 2011</td>
<td></td>
</tr>
<tr>
<td>Vitality</td>
<td>1 (7)</td>
<td>Salbach et al. 2014</td>
<td></td>
</tr>
<tr>
<td>Activity</td>
<td>11 (73)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical function</td>
<td>1 (7)</td>
<td>Stuart et al. 2009</td>
<td></td>
</tr>
<tr>
<td>Participation</td>
<td>7 (47)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community reintegration</td>
<td>1 (7)</td>
<td>Hassett et al. 2009</td>
<td></td>
</tr>
<tr>
<td>Contextual factors: Personal</td>
<td>5 (15)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illness views/perceptions</td>
<td>1 (7)</td>
<td>Poliakoff et al. 2013</td>
<td></td>
</tr>
<tr>
<td>Goal attainment†</td>
<td>1 (7)</td>
<td>Hassett et al. 2009</td>
<td></td>
</tr>
<tr>
<td>Medication dosage</td>
<td>1 (7)</td>
<td>Corcos et al. 2013</td>
<td></td>
</tr>
<tr>
<td>Contextual factors: Environmental</td>
<td>4 (27)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived relatedness</td>
<td>1 (7)</td>
<td>Poliakoff et al. 2013</td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td>1 (7)</td>
<td>Sims et al. 2009</td>
<td></td>
</tr>
</tbody>
</table>

**Non-ICF Outcomes**

*Includes body mass index, waist-to-hip-ratio, waist circumference.
†3-month goal relating to intervention, 6-month goal relating to return to physical activity.
Figure 3.1. Process for study selection.

Articles or records identified through databases (n=2062)
MEDLINE: 871; CINAHL: 614;
EMBASE: 567; CDSR: 10

Additional articles identified through other sources (n=5)

Titles/abstracts screened after duplicates removed (n=1785)

Records excluded (n=1648)

Full-text articles assessed for eligibility (n=137)

n=119 full-text articles excluded:
1) Not delivered by fitness instructor (45 articles)
2) Only available as conference abstracts (43 articles)
3) Not community-based (27 articles)
4) Study objective was not to evaluate an exercise programme (4 articles)

18 articles describing 15 studies were included in the scoping review
### Table 3.1S. Characteristics of included studies (n=15 studies represented in n=18 articles)

<table>
<thead>
<tr>
<th>First Author Year Study Design Country</th>
<th>Clinical Population Total Sample Size</th>
<th>Eligibility Criteria</th>
<th>Exercise Programme</th>
<th>Setting</th>
<th>HCP Involved</th>
<th>Study Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corcos 2013 2-group RCT</td>
<td>PD N=48</td>
<td>Inclusion: 1) Patients with idiopathic PD. 2) Moderate disease severity 3) Ages 50 to 67 years 4) On stable dopaminergic</td>
<td>Frequency: 2 classes/week Programme duration: 104 weeks Strength training exercises</td>
<td>Personal trainer (directed 2 classes/week 0-6 mon, 1</td>
<td>Gym</td>
<td>No</td>
</tr>
<tr>
<td>Combs 2013 2-group RCT</td>
<td>PD N=31</td>
<td>Inclusion: 1) Clinical diagnosis of PD 2) Age ≥21 3) Currently not receiving physical therapy services 4) Independently ambulatory in the home setting with or without use of assistive aid 5) Able to follow at least three step verbal commands 6) Available for entire study period 7) Had transportation to and from study sessions Exclusion: 1) Pre-existing neurological conditions other than PD 2) Current musculoskeletal or cardiovascular conditions that would limit participation in either training programme 3) Orthopedic surgery within the past six months 4) Past brain surgery or brain stimulator implant 5) Current known pregnancy</td>
<td>Frequency: 2-3 classes/week Programme duration: 12 weeks Class duration: 1.5 hours Programme format: group Stand-alone Group size: NR</td>
<td>Boxing training, self-progressed: Warm-up, stretching, boxing (e.g., lateral foot work, punching bags), resistance exercises (e.g., push-ups), aerobic training</td>
<td>1-2 certified personal trainers</td>
<td>Rock Steady Boxing Foundation</td>
</tr>
<tr>
<td>Quantitative therapy</td>
<td>Patients were ineligible if they had a neurological history other than PD</td>
<td>Able to walk for 6 minutes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td>----------------------------------------------------------------------------</td>
<td>---------------------------</td>
<td></td>
<td></td>
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<tr>
<td>USA</td>
<td>Significant arthritis</td>
<td>Exclusion:</td>
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<td></td>
<td>3) Failed the Physical Activity Readiness Questionnaire</td>
<td>1) Able to walk for 6 minutes</td>
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<td></td>
<td>4) Had cognitive impairment (indicated by a Mini-Mental State Examination score &lt;23)</td>
<td>Exclusion:</td>
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<td></td>
<td>5) Were already exercising</td>
<td>1) Inclusion:</td>
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<td></td>
<td>6) Had undergone surgery for PD</td>
<td>1) Age ≥18</td>
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<tr>
<td></td>
<td>Class duration: NR</td>
<td>2) Able to engage with training in an exercise facility/gym</td>
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<td>3) Able to walk 10m using assistance/aid</td>
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<td>individual Group size: NA</td>
<td>4) Able to participate for the duration of the study</td>
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<td>5) Patients were ineligible if they had a neurological history other than PD</td>
<td>Exclusion:</td>
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<td>6) Significant arthritis</td>
<td>1) Unable to meet study criteria</td>
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<td>7) Failed the Physical Activity Readiness Questionnaire</td>
<td>2) Had contraindications to exercise</td>
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<td>8) Had cognitive impairment (indicated by a Mini-Mental State Examination score &lt;23)</td>
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<td>9) Were already exercising</td>
<td>1) Unwilling to participate in programme</td>
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<td>10) Had undergone surgery for PD</td>
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<th>Programmes</th>
<th>Inclusion:</th>
<th>Exclusion:</th>
<th>Frequency:</th>
<th>Class duration:</th>
<th>Fitness professionals</th>
<th>Community gym – Inclusive Fitness Initiative gym</th>
<th>Yes (PT)</th>
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<tr>
<td>Elsworth 2011</td>
<td>PD, CP, MS, motor neuron disease, neuromuscular disorders, TBI, transverse myelitis</td>
<td>N=99 N=39</td>
<td>Self-directed. included aerobic, muscle strength and flexibility exercises</td>
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<td>Fitness professionals</td>
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<td>Tango dance instructor</td>
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<td>Dance instructor</td>
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<td>United Kingdom</td>
<td>Frequency: 2 classes/week</td>
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<td>Foster 2013</td>
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<td>2) Classified as Hoehn and Yahr stages I to IV</td>
<td>1) History of neurologic deficit other than PD</td>
<td>2) Motor benefit from levodopa</td>
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<td>3) Experienced motor benefit from levodopa</td>
<td>2) Serious medical problem(s)</td>
<td>3) Evidence of abnormality other than PD-related changes on brain imaging</td>
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<td>4) Able to walk independently for 3m with or without an assistive device</td>
<td>3) Evidence of abnormality other than PD-related changes on brain imaging</td>
<td>4) History or evidence of musculoskeletal or psychological problems</td>
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<td>Stroke</td>
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<td>At least 50 years of age at the time of stroke</td>
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<td>Quantitative &amp; Qualitative</td>
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<td>Return to living in the community for at least three months</td>
<td>1) People living in nursing homes</td>
<td>2) Felt able to participate in group activities</td>
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<td>Reed et al 2009</td>
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<td>Frequency: 2 classes/week</td>
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<td>Warm up, tailored and progressive exercises to improve balance, endurance, strength, flexibility, function and well-being completed in a circuit</td>
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<td>Home exercise manuals</td>
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<td>-healthcare system costs (e.g., primary care consultations)</td>
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<td>-social care costs (e.g., home care)</td>
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<td>-cost of intervention (e.g., hire of the venue)</td>
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<td>Exclusion</td>
<td>Frequency</td>
<td>Programme duration</td>
<td>Programme format</td>
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<tr>
<td>Hassett 2009</td>
<td>2-group RCT</td>
<td>Australia</td>
<td>62</td>
<td>Inclusion: &lt;br&gt; 1) Had at least a very severe TBI &lt;br&gt; 2) Inpatient hospital admission of &gt; 1 month &lt;br&gt; 3) Able to walk independently at a speed ≥1 m/sec in a 10-m walk test &lt;br&gt; 4) Able to commit 3 h per week to an exercise programme on discharge &lt;br&gt; 5) Living within a reasonable travelling distance (not &gt;3 h) from 1 of the 3 units</td>
<td>Exclusion: &lt;br&gt; Patients excluded if the treating medical specialist and site investigator determined they had any: &lt;br&gt; 1) concurrent medical condition for which moderate to high intensity exercise was contraindicated &lt;br&gt; 2) cognitive or language impairments affecting ability to understand verbal instructions &lt;br&gt; 3) behavioural problems inappropriate in a fitness centre environment</td>
<td>Frequency: 3 classes/week &lt;br&gt; Programme duration: 12 weeks &lt;br&gt; Class duration: 1 hour</td>
<td>Warm up, strength training, cardiovascular fitness training, cool-down, goal setting</td>
<td>Personal trainer</td>
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<td>Hoffman 2010</td>
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<td>USA</td>
<td>80</td>
<td>Inclusion: &lt;br&gt; 1) Self-reported TBI severe enough to have required medical evaluation or hospital admission after injury &lt;br&gt; 2) Time since TBI 6 months to 5 years &lt;br&gt; 3) at least a mild level of</td>
<td></td>
<td>Frequency: 1 class/week &lt;br&gt; Programme duration: 10 weeks &lt;br&gt; Class duration: 1 hour</td>
<td>Warm-up, aerobic exercise (30 minutes), cool-down. &lt;br&gt; Home exercise programme (30 minutes of)</td>
<td>Research educational trainer and certified athletic trainer</td>
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<td>Programme format:</td>
<td>Gym staff</td>
<td>Local leisure complex</td>
<td>Outcome measures</td>
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<td>Poliakoff 2013</td>
<td>PD</td>
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<td>1) Diagnosed/ suspected dementia 2) Attendance of a group exercise class for PD or other neurodegenerative disease 3) &gt;2 weeks holiday booked during the study period</td>
<td>Frequency: 2 classes/week biweekly</td>
<td>Group</td>
<td>No 4) Strength training 5) Accredited fitness trainer 6) Community gym</td>
<td>reaction time - motor functioning - coordination - mobility - strength -QL - illness perceptions - “perceived relatedness” in exercise - “views on gym intervention”</td>
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<td>7) reactive exercise - locus of control - optimism - self-esteem</td>
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<tr>
<td>Poliakoff 2013</td>
<td>PD</td>
<td>NR</td>
<td>1) Diagnosed/ suspected dementia 2) Attendance of a group exercise class for PD or other neurodegenerative disease 3) &gt;2 weeks holiday booked during the study period</td>
<td>Frequency: 2 classes/week biweekly</td>
<td>Group</td>
<td>8) perception of exercise - perceptions of health - self-efficacy - social support</td>
<td>participation - HRQL</td>
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<td>N=32</td>
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<td>Programme duration: 20 weeks</td>
<td>Class duration: 1 hour</td>
<td>Gym staff</td>
<td>9) perception of exercise - perceptions of health - self-efficacy - social support</td>
<td>participation - HRQL</td>
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<tr>
<td>Sims 2009</td>
<td>Stroke</td>
<td>1) Stroke 2) depression (PSE) post stroke</td>
<td>1) Stroke &lt;6 months ago</td>
<td>Frequency: 2 classes/week</td>
<td>Group Stand-alone</td>
<td>No 4) Strength training 5) Accredited fitness trainer 6) Community gym</td>
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<td>Stroke</td>
<td>1) Stroke 2) depression (PSE) post stroke</td>
<td>1) Stroke &lt;6 months ago</td>
<td>Frequency: 2 classes/week</td>
<td>Group Stand-alone</td>
<td>No 4) Strength training 5) Accredited fitness trainer 6) Community gym</td>
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<td>Programme duration: 10 weeks</td>
<td>Class</td>
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<td>participation - HRQL</td>
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<tr>
<td>Australia</td>
<td>2) Inability to walk a distance of at least 20 m independently with or without assistive device 3) Age &lt;18 4) Prime-MD Patient Health Questionnaire score &lt;5 5) Depression with psychotic features 6) Alcohol or drug related depression 7) Schizophrenia 8) Bipolar disorder 9) other psychiatric diagnoses 10) Suicidal ideation 11) Dementia 12) Terminally ill 13) Uncontrolled hypertension 14) Unstable insulin dependent diabetes 15) Unstable angina 16) Medical clearance</td>
<td>duration: NR</td>
<td>group</td>
<td>small groups</td>
<td>-strength -social support -QL</td>
<td></td>
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<tr>
<td>Italy</td>
<td>1) Chronic phase of stroke recovery and have a mild-to-moderate hemi-paretic gait 2) At least 40 years of age 3) time post-stroke &gt; 9 months 4) Have no comorbid conditions, such as dementia, aphasia with inability to follow 2-step commands, symptomatic heart failure, unstable angina, and hypertension 5) Medical clearance</td>
<td>Frequency: 3 classes/week Programme duration: 24 weeks Class duration: 1 hour</td>
<td>group</td>
<td>Stand-alone</td>
<td>Progressive walking practice, functional strength training (e.g., squats), functional balance training (e.g., walking over ropes as obstacles), sit to stand, etc.</td>
<td>Gym instructors</td>
<td>Local gyms</td>
<td>Yes (PT)</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Sample Size</td>
<td>Inclusion</td>
<td>Frequency</td>
<td>Programme Format</td>
<td>Fitness Instructor</td>
<td>Leisure Location</td>
<td>Notes</td>
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</table>
| Cramp 2010    | Time series experimental design | Stroke N=18 | 1) First unilateral stroke resulting in motor impairment of lower limb  
2) 3–12 months post-onset  
3) Able to walk independently with or without assistive devices  
4) Able to follow simple instruction  
Exclusion:  
1) Uncontrolled hypertension or cardiac conditions  
2) Comorbid neurological conditions  
3) Joint or muscular problems affecting lower extremities  
4) Illnesses preventing full participation in the programme  
5) Receiving ongoing rehabilitation | Frequency: Self-directed, participants asked to attend minimum 16 classes. Classes available 2 times/week at closest centre  
Programme duration: 14 weeks  
Class duration: 1-1.5 hours  
Programme format: group  
Stand-alone  
Group size: 6 | Warm-up, progressive resistance exercise and practice of functional tasks (sit-to-stand, stepping) organized in a circuit, cool-down | Fitness instructor | Leisure centres | Yes (PT)  
- muscle strength  
- muscle tone  
- walking speed  
- walking distance/endurance  
- balance (functional)  
- ADL, IADL  
- feasibility |
| Kilbride 2013 | Pragmatic mixed methods | Stroke N=30 | Inclusion:  
1) Community-dwelling stroke survivors (ambulatory or wheelchair users)  
2) Able to give informed consent  
3) Have finished formal physical rehabilitation  
4) Able to follow simple instructions  
5) Medical clearance  
6) Independent standing balance for a minimum of 2 minutes | Frequency: 1 class/week  
Programme duration: 12 weeks  
Class duration: 1.5 hours  
Programme format: group  
Multi-component  
Group size: 8 | Aerobic endurance, functional movement with task-related exercises - strengthening, - range of movement, - balance, - coordination  
Includes a psychological | Two trained instructors | Leisure centre | No  
- strength (postural control)  
- balance (functional)  
- walking speed  
- participation  
- experiences |
<table>
<thead>
<tr>
<th>Kingdom</th>
<th>7) cognitive ability to follow simple instructions</th>
<th>intervention</th>
<th>Fitness instructors</th>
<th>Community centres</th>
<th>Yes (PT)</th>
<th>Entire sample (n=14):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salbach 2013</td>
<td>Inclusion:</td>
<td>Frequency: 2 classes/week Programme duration: 12 weeks Class duration: 1 hour</td>
<td>Fitness instructors</td>
<td>Community centres</td>
<td>Yes (PT)</td>
<td>-safety</td>
</tr>
<tr>
<td>Pilot before and after study</td>
<td>Diagnosis of stroke, ABI or MS confirmed by the individual’s physician</td>
<td>Programme format: group Stand-alone Group size: 8</td>
<td></td>
<td></td>
<td></td>
<td>-feasibility</td>
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<tr>
<td>Quantitative and Qualitative</td>
<td>Age ≥18</td>
<td>Task-oriented exercise targeting strength, balance, and mobility</td>
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<td>People with stroke, ABI, MS (n=12):</td>
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<tr>
<td>Canada</td>
<td>Ability to walk a minimum of 10 meters with or without walking aids without assistance from another person</td>
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<td>Living in the community</td>
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<td></td>
<td>Ability to follow verbal instructions or demonstrations of the exercises</td>
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<td></td>
<td>Medical clearance from the participant’s physician</td>
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<td>Exclusion:</td>
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<td>-walking</td>
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<td></td>
<td>Involvement in another formal exercise or rehabilitation programme</td>
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<td></td>
<td>Conditions or symptoms preventing participation in exercise (e.g., unstable cardiovascular disease, significant joint pain)</td>
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<td></td>
<td>Cognitive or behavioural deficits preventing cooperation within a group</td>
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<td></td>
<td>People with MS with an unstable disease course or an exacerbation within 3 months of starting the exercise programme. Exclusion criteria 2-4 based on judgment of participant’s physician who completed medical</td>
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<td></td>
<td>Frequency: 2 classes/week Programme duration: 12 weeks Class duration: 1 hour</td>
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<td>Focus group:</td>
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<td></td>
<td>Task-oriented exercise targeting strength, balance, and mobility</td>
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<td>-perceived</td>
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<tr>
<td></td>
<td>Fitness instructors</td>
<td>Community centres</td>
<td>Yes (PT)</td>
<td>Entire sample (n=14):</td>
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<tr>
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<td>-safety</td>
<td>-feasibility</td>
<td>People with stroke, ABI, MS (n=12):</td>
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<td>-balance</td>
<td>-confidence</td>
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<td>-walking</td>
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<td>(functional)</td>
<td>-participation</td>
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<td>-participation</td>
<td>Focus group:</td>
<td>perceived</td>
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<td>-safety</td>
<td>feasibility,</td>
<td>impact</td>
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<td>Study</td>
<td>Study Design</td>
<td>Setting</td>
<td>N</td>
<td>Inclusion</td>
<td>Frequency</td>
<td>Programme duration</td>
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</table>
| Combs 2011   | Case series  | Quantitative | 6 | 1) Diagnosis of PD  
2) Aged ≥21  
3) Currently not receiving PT  
4) Able to ambulate independently in the home, with or without an assistive device  
5) Able to follow at least 3-step verbal commands  
6) Available for the entire course of the case series  
7) Self-transportation | Frequency: 2-3 classes/week  
Programme duration: 12 weeks  
Class duration: 1.5 hours  
Programme format: group  
Stand-alone  
Group size: NR | Boxing training, self-progressed: Warm-up, stretching, boxing (e.g., lateral foot work, punching bags), resistance exercises (e.g., push-ups), aerobic training | 1-2 personal trainers | Rock Steady Boxing Foundation | No |
| N=6           | USA          | USA     |   |                                                                            |           |                    |                 |           | gait cadence -stride length -step width -motor functioning -balance confidence -balance (functional) -mobility -walking distance/endurance -walking speed -ADL -QL -feasibility -safety |
| Wiles 2008   | Qualitative  | United Kingdom | 30 | 1) A primary diagnosis of stroke.  
2) Referred to the exercise on prescription (EoP) scheme | NR | Programme duration: NR  
Class duration: NR  
Programme format: Individual  
Stand-alone  
Group size: NA | NR | HCP referred individuals for assessment by fitness instructor who develops gym-based exercise programme. A PT may attend the first session to advise on | Fitness instructor | Leisure centres | Yes (PT) | -from objectives: appropriateness and acceptability of exercise scheme for people with stroke |
Abbreviations: PD, Parkinson’s disease; MS, multiple sclerosis; ABI, acquired brain injury; CP, cerebral palsy; TBI, traumatic brain injury; PT, physical therapist; m, metres; RCT, randomized controlled trial; HCP, healthcare professional; NR, not reported; NA, not applicable; QL, Quality of life; ADL, Activities of Daily Living; IADL, instrumental activities of daily living; HRQL, Health-Related QL; USA, United States of America.

*Individual format involves one-on-one exercise, group format involves multiple participants in the programme, stand-alone involves the exercise programme only, and multi-component involves the exercise programme and an education scheme.

appropriate exercises. Classes led by practitioners are not included in EoP schemes. User follows an individualised programme in a gym, usually in a session for those referred to the EoP scheme.

Classes led by practitioners are not included in EoP schemes. User follows an individualised programme in a gym, usually in a session for those referred to the EoP scheme.
CHAPTER FOUR

Manuscript:

Impact of a Community Exercise Program Involving a Healthcare-Recreation Partnership in People with Neurological Conditions and their Caregivers

Merali, S., Cameron, J.I., Barclay, R., & Salbach, N.M.

This manuscript will be submitted for consideration for publication to the journal

Physical Therapy.

Note: Detailed descriptions of the methods used in the qualitative study are presented beyond what would be expected in a manuscript submitted for publication
Abstract

**Background:** Community-based exercise programs incorporating a healthcare-recreation partnership (CBEP-HRP) provide an ideal model for health maintenance/improvement (e.g., the Together in Movement and Exercise (TIME™) program). This study aimed to explore the perceived impact of the TIME™ program on physical function, participation in meaningful activities, caregiver assistance and caregiver health among people with neurological conditions and their caregivers. The secondary objective was to understand participants’ and caregivers’ preferences for the content and timing of education about CBEPs.

**Methods:** A descriptive qualitative study involving in-depth face-to-face or telephone interviews was conducted. Inclusion criteria for individuals with a neurological condition included balance and mobility deficits as a result of the neurological condition, registered in a CBEP-HRP, and presence of a caregiver. Individuals with a neurological condition and their caregivers were recruited from community centres offering the TIME™ program. Interviews were audio-recorded, transcribed verbatim, and reviewed for accuracy. Thematic analysis was performed.

**Results:** Thirteen (54% male) individuals with a neurological condition (stroke: n=9; multiple sclerosis: n=4) and 12 (62% female) caregivers were interviewed. The median age of the participants and caregivers was 59 and 61 years, respectively. Two themes emerged suggesting TIME™ program participants experienced interrelated improvements in body function, activities and participation that were reinforced through repeated registration in the program, and caregivers experienced both challenges (e.g., transportation) and benefits (e.g., reduced caregiver assistance, improved mental health) associated with the TIME™ program. Additionally, enhancing access to CBEP-HRPs requires education, motivation, assistance and involvement of caregivers, and government funding.
**Conclusion:** Task-oriented training performed in the community setting using the CBEP-HRP model has similar perceived benefits to training performed in the healthcare setting, suggesting successful translation from the healthcare to the community setting. Findings highlight new information about the impact of the TIME™ program on caregivers, provide directions for future research and program development, such as incorporating body function, activity, and participation as program outcomes, establishing long-term benefits of exercise participation for widespread implementation, examining the need for exercise programs for caregivers, and developing marketing strategies for CBEPs to increase awareness.

**Keywords:** brain diseases, exercise, caregivers, qualitative, social participation
4.1 INTRODUCTION

Individuals with neurological conditions, such as stroke and multiple sclerosis (MS), experience chronic balance and mobility limitations that contribute to low levels of physical activity and deconditioning.\textsuperscript{12-15} Approximately 75-83\% of individuals with stroke and MS are affected by balance impairment\textsuperscript{44, 51} and 75-90\% by mobility limitation.\textsuperscript{36, 159} Physical inactivity increases the risk of negative health events, such as cardiovascular disease,\textsuperscript{160} increased healthcare utilization,\textsuperscript{161} and decreased activities of daily living (ADL) function\textsuperscript{47} and participation in meaningful activities.\textsuperscript{47}

Physical inactivity results in decreased independence in performing everyday activities and a need for caregiver assistance. As a result of providing this assistance, caregivers can experience negative health outcomes.\textsuperscript{162, 163} In addition to the physical assistance delivered by caregivers, caregiving can impact all areas of the caregiver’s life, and can lead to reduced physical well-being, social isolation, emotional and psychological stress, diminished overall quality of life, and financial strain.\textsuperscript{17, 19}

Ongoing opportunities for individuals with a neurological condition to safely exercise in the community are needed as they help individuals to maintain or improve health and may also reduce the need for caregiver assistance.\textsuperscript{92} Community-based exercise programs incorporating a healthcare-recreation partnership (CBEP-HRP) provide an ideal model for increasing access to safe and appropriate exercise for people with balance and mobility limitations.\textsuperscript{92} We define CBEPs as structured instructional programs of physical activity for groups or individuals delivered outside of the healthcare setting and available in community or recreation centres.\textsuperscript{103} The healthcare-recreation partnership component refers to the involvement of registered healthcare professionals (HCP) with expertise prescribing exercise for the targeted clinical
population (typically a physical therapist (PT))\textsuperscript{103}, to train and support fitness instructors to deliver exercise programs.\textsuperscript{92} The CBEP-HRP model has been evaluated in people with various neurological conditions, including stroke and MS.\textsuperscript{103} Exercise programs in these studies offered 2-3 classes per week, with a 0.75-1 hour class duration, and program duration of 8-52 weeks.\textsuperscript{121,128,132,138,140} Group, task-oriented exercise programs targeting balance and mobility are particularly feasible to implement within a CBEP-HRP model.\textsuperscript{92} Group exercise programs enable social support, and increase confidence and self-efficacy.\textsuperscript{154} Task-oriented training involves the repetitive and progressive practice of functional activities that are relevant to daily life. Results from systematic reviews show that task-oriented training is effective in improving balance and walking capacity in people post-stroke.\textsuperscript{26,32} Implementation of group, task-oriented exercise programs targeting balance and mobility limitations using the CBEP-HRP has proven safe, feasible and potentially beneficial for people with neurological conditions.\textsuperscript{84,92}

A scoping review of the literature describing evaluations of CBEPs delivered by fitness instructors in people with neurological conditions\textsuperscript{103} revealed that the most commonly examined outcomes were health-related quality of life and balance. Studies examining physical function, ADLs and participation were limited. These outcomes are particularly important as results from focus groups conducted in previous research\textsuperscript{92} suggest that improvement in balance, mobility, and ADL function associated with CBEP-HRPs can reduce the need for caregiver assistance and enable community reintegration and participation in meaningful activities for both the exercise participant and caregiver. This previous study was not designed to specifically examine the impact on caregiver outcomes, however, and only two caregivers participated.

No studies in the scoping review explored the impact of CBEPs delivered by fitness instructors on caregiver health (i.e., physical and mental/emotional health).\textsuperscript{103} Only two studies\textsuperscript{84,
assessed caregiver burden quantitatively using the Caregiver Strain Index (CSI), but neither study observed decreases in caregiver burden. A reason for this may be due to the binary yes/no response scale of the CSI which may be limited in detecting change in caregiver burden.

Little is known about the effects of group, task-oriented CBEP-HRP on participation in people with a neurological condition or caregiver health. A more comprehensive understanding of how involvement in these programs affects physical function, participation, caregiver assistance and health is needed. Qualitative research methodology is well-suited to gain an in-depth understanding of the experiences of people with neurological conditions and their caregivers in CBEPs. Therefore, the objective of this study was to explore the perceptions of people with neurological conditions and their caregivers on the effects of a group, task-oriented CBEP-HRP called Together in Movement and Exercise (TIME™ ) on physical function (balance, mobility, ADL function), participation in meaningful activities, caregiver assistance and caregiver health. The secondary objective was to understand participants’ and caregivers’ preferences for the content and timing of education about CBEP-HRPs.

4.2 METHODS

4.2.1 Study Design

A descriptive qualitative study involving in-depth face-to-face or telephone interviews was conducted. Descriptive qualitative studies offer a comprehensive summary of an event in the everyday terms of those events. Researchers conducting descriptive qualitative studies pursue an accurate description of 1) events and that most individuals (i.e., researchers and participants) would be in agreement regarding the accuracy of the description when witnessing the same event; and 2) meanings participants attributed to those events. Qualitative descriptive
studies involve remaining closer to the data, and offer less interpretation than other approaches such as grounded theory (i.e., the development of a theory or conceptual model through the experiences of individuals) and phenomenology (i.e., describing the “lived experience” of an individual with the awareness that reality is built on an individual’s perceptions and has the ability to change across time), which incorporate the researchers own interpretation of what is seen or heard. Both of these approaches require interpretation of the data beyond the goals of the study, which involved describing the experiences of individuals with neurological conditions and their caregivers in a concise and descriptively rich manner, as well as remaining close to the data with low-inference.

4.2.2 Participants

Individuals with balance and mobility limitations as a result of a neurological condition registered in a group, task-oriented CBEP-HRP and their caregivers were recruited. Inclusion criteria were: 1) self-reported diagnosis of a neurological condition; 2) self-reported balance and mobility deficits as a result of a neurological condition; 3) registered in a group, task-oriented CBEP-HRP targeting balance and mobility limitations (i.e., the TIME™ program; to register participants must have medical clearance, ability to walk a minimum of 10 meters independently with or without the use of an ambulatory aid, and sufficient cognitive function (i.e., able to follow verbal instructions or exercise demonstrations)); 4) presence of a caregiver; 5) age ≥18 years; and 6) able to speak and read English. Individuals with moderate to severe aphasia in the judgment of the TIME™ instructor were excluded due to the interviewer not being trained in supportive communication required to interview individuals with moderate to severe aphasia. Inclusion criteria for caregivers were: 1) helping the individual with a neurological condition to live independently at home and provide support and assistance with basic and instrumental
ADLs at least once a week; and 2) able to speak and read English. Individuals who were paid personal support workers were excluded. Initially, caregivers were limited to those over the age of 18 years. However, this limited the pool of potential participants and made recruitment challenging within the short timeframe of the study. As a result, the inclusion criteria were broadened to include teenaged individuals involved in care.

4.2.3 Sampling and Recruitment

As individuals entered the study, we monitored the number of individuals who were registered in the TIME™ program for the first time (“first-time registrants”) and who had registered in the program again after previously completing at least one TIME™ program (“re-registrants”). The number of TIME™ sessions completed was expected to influence perceptions of program impact on physical function, participation and caregiver burden and health.

People with a neurological condition and their caregivers were recruited from 11 community centers in Ontario, Canada offering the TIME™ program. At 5 local sites, TIME™ program coordinators notified individuals with a neurological condition about the study and either provided them with an envelope containing a study brochure (Appendix I) and consent forms for both the individual with a neurological condition and their caregiver (Appendices C & D) or placed envelopes at the registration desk. The first author either visited classes or set up a study information booth outside of the class to answer questions and register interested individuals. At 6 remote sites, the TIME™ program coordinators provided potential participants with an envelope containing a study brochure and consent form and instructed interested individuals and caregivers to contact the researcher directly. At all sites, a recruitment poster was displayed on an information bulletin board (Appendix J). Individuals and their caregivers were
screened for eligibility (Appendices P & Q), provided consent, and an interview was conducted following completion of the exercise program.

Prior to commencing recruitment, the study was submitted and approved by the University of Toronto Research Ethics Board. The exercise participant and caregiver consent forms (Appendices C & D) included detailed information regarding the study procedures (i.e., background and purpose of the study, who is invited to participate, what does participation in the study involve, conditions for participating, potential risks and benefits, privacy and confidentiality, compensation, and contact information). For interviews conducted in person, participants were provided with a consent form to read and sign. For interviews conducted by telephone, the consent form was read to the participant and verbal consent was obtained. All study participants provided written or verbal informed consent.

4.2.4 Exercise Program

The TIME™ program consisted of a one-hour group class offered to a maximum of 8-16 participants either once or twice per week for 6-12 weeks across study sites. Each class was run by at least one fitness instructor and 1-2 volunteers to obtain the recommended ratio of 1 staff/volunteer per 4 participants. Fitness instructors were trained by PTs to deliver the program as outlined in the TIME™ toolkit. Classes involved a seated warm-up (10-15 minutes), exercises with varying levels of difficulty, and cool-down (5-10 minutes). Sites delivered the TIME™ program according to an earlier 9-station version (i.e., seated reaching, sit to stand & walk between chairs, tap-up or standing & reaching, heel & toe raises or walking variations, standing weight shifts, dance steps, step-ups, aerobic station, arm range & motion) or the modified 3-superstation version (i.e., superstation 1: walking, wall work, use of aerobic
equipment; superstation 2: standing weight shifts, dance steps; and superstation 3: tap-ups, step-ups, heel and toe raises, hamstring curls, marching-on-the-spot, mini-squats).

4.2.5 Data Collection

Two semi-structured interview guides, one for individuals with a neurological condition (Appendix G) and one for caregivers (Appendix H), were developed and pilot tested with one participant-caregiver dyad to examine the clarity and order of questions. Interviews with the participants and caregivers were conducted separately and consisted of open-ended questions. Participants were asked to describe: a) the history and experience of the neurological condition; b) the impact of the neurological condition; c) discovering or choosing the exercise program (i.e., TIME™ program); d) educational preferences for facilitating access to CBEP-HRPs; and e) physical function, abilities to perform ADLs, participation in meaningful activities, and caregiver assistance following involvement in the TIME™ program. Caregivers were asked: a) their experience when their family member was affected by the neurological condition; b) their experience caring for someone with a neurological condition; c) discovering or choosing the exercise program (i.e., TIME™ program); d) educational preferences for facilitating access to CBEP-HRPs; e) perceptions of changes in the family members’ independence, caregiver assistance, caregiver health and participation in meaningful activities following involvement of the family member in the TIME™ program; and f) caregiver engagement with the individual in the TIME™ program.

The interviewer used probing questions to obtain clarification or greater detail. An example of probing included the participant being asked whether participation in the TIME™ program changed their physical function. Probing for greater detail was used to ask about their balance, walking ability, and ability to use the stairs when participants did not talk about it
themselves. See Table 4.1 for sample interview questions. Interviews were conducted face-to-face in a location convenient for the study participants or by telephone.\textsuperscript{171} Although there is some controversy regarding data quality with telephone interviews versus face-to-face interviews, there is no evidence regarding the superiority of one method over the other.\textsuperscript{171} Interviews were audiotaped and professionally transcribed verbatim. Reflective notes were taken following each interview. To maintain data quality, each transcript was read while listening to the audiotape to verify accuracy.

Following the interview, participants provided socio-demographic and clinical data. People with neurological conditions completed questionnaires assessing their ability to perform basic ADL and physical activity using the Barthel Index\textsuperscript{40} (BI) and the Community Health Activities Model Program for Seniors\textsuperscript{172} (CHAMPS), respectively (see measures in Appendices U & V). Evidence of validity of the BI and CHAMPS have been shown in neurological populations (i.e., stroke) and in older adults, respectively.\textsuperscript{172, 173} The BI index is a 10-item questionnaire. The total scoring ranges from 0-100, with higher scores indicating individuals are more independent.\textsuperscript{40} The CHAMPS items were categorized into 4 domains (i.e., walking (items 24-28), moderate-intensity physical activity (items 7, 9, 15, 16, 19, 21, 23, 26, 29-33, 36-38, 40), vigorous-intensity physical activity (items 14, 24, 25), and total participation (items 1-40)).\textsuperscript{172} Metabolic equivalent (MET) values were assigned to each item. MET values ≥3.0 indicated moderate-intensity aerobic activity.\textsuperscript{172} MET values ≥6.0 indicated vigorous-intensity aerobic activity. To determine the level of assistance provided, caregivers completed the Caregiver Assistance Scale\textsuperscript{163, 174} (CAS). The CAS is a 17-item questionnaire assessing the amount of assistance provided by the caregiver with ADLs, instrumental ADLs and treatment related activities (Appendix W).\textsuperscript{163} Each item is scored on a 7-point Likert scale from 0=no assistance
provided to $6=\text{a lot of assistance provided.}$. The total scoring ranges from 0-102, with higher scores indicating more assistance was provided. The items with the highest amount of assistance required were reported. For the interviews conducted by telephone, the questionnaires were mailed to the participants, who then completed and mailed them back to the researcher. A gift card and a thank you letter were mailed to participants on completion of the interview.

Confidentiality of participants was maintained by providing each participant with an identification code upon acceptance into the study. They were identified by this ID code in all the records and transcripts. Only the researchers of the study had access to the master code list containing the names of the participants associated with each ID number. Upon completion of the study (i.e., data analysis), this list would be destroyed. The master code list was stored separately from the study data.

Interview data were recorded digitally on audio files. Following each interview, the researcher transferred the audio files to a secure server (Dropbox) to share with a professional transcriptionist. The audio file was then erased from the digital recorder so that the researcher would not be carrying confidential information within the community. The audio files were copied and kept in a secure server (the server in the Department of Physical Therapy at the University of Toronto) and were deleted from Dropbox. Transcripts were electronic word files. All paper files (e.g., sociodemographic data, CHAMPS, and CAS questionnaires) were scanned and stored on the secure server in the Department of Physical Therapy and placed in a filing cabinet under lock and key at the University of Toronto. Only the investigator, supervisor, and co-investigator had access to the cabinet. Data will be retained for 10 years after the completion of the study. At this point, files will be deleted from the server and transcripts will be destroyed.

4.2.6 Sample Size
The estimated sample size to reach data saturation (where no new information is obtained) was 12 participants with a neurological condition and 12 caregivers. The sample sizes were based on previous research examining stroke survivors’ perceived needs of a community-based exercise and education scheme through the use of semi-structured in-depth interviews. Data saturation was reached with 12 individuals with stroke.

4.2.7 Data Analysis

Data sources included interview transcripts and reflective notes. Thematic content analysis was performed through open-coding transcripts line-by-line using NVivo 10, a qualitative data analysis software. Three authors open-coded four transcripts and reflective notes (two from individuals with a neurological condition and two from caregivers) independently, and met to review and discuss codes. Coding involved multiple steps, beginning with familiarization and immersion in the data through repeated reading of the transcripts. During this active reading, the researcher looked for meanings, patterns, and first thoughts and impressions. The next step involved the generation of initial codes regarding what was in the data and what was interesting. A code is “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon”. After the initial review and coding of the transcripts, the researcher was left with a list of various codes identified from the data (i.e., codebook). Once the codebook (Appendix S) was developed, reviewed, and revised by three authors, the codes were applied to each transcript. The next step was to sort the coded data into broader level themes. Once a set of themes were identified, the next step was to review and refine the themes. It was in this step that some themes collapse into larger themes, while others are omitted or broken down into separate or sub-themes. Next, the themes were defined and further refined, and each theme was considered on its own and in relation to others. In this
step, the researcher conducted a detailed analysis of each theme, identifying the story behind each theme, how the theme fit into the broader overall story in relation to the research objectives, and minimizing overlap between themes.\textsuperscript{168, 176} The process of determining themes was done during two meetings with all authors to minimize bias.\textsuperscript{178}

The terminology of the International Classification of Functioning, Disability and Health (ICF) framework, such as body function/structure, activities and participation, was used when appropriate.\textsuperscript{179} The terminology of the framework was chosen as it aligned with the objectives of the study and is a universal language and framework for HCPs and researchers to use when describing health and health-related states.\textsuperscript{179} Comparisons were also made between first-time and re-registrants of the TIME™ program through frequency of responses. Participant and caregiver data were analyzed separately using memos to explore similarities and differences in their experiences. Descriptive statistics were used to summarize quantitative data on socio-demographic and clinical characteristics using Microsoft Excel.

4.2.8 Strategies to Ensure Trustworthiness

Strategies such as: 1) transparency, by providing a clear account of the procedures used and keeping an audit trail, 2) maximizing reliability, by taking reflective notes, reviewing transcripts while listening to audio files, discussing coding with other authors, 3) raising information one individual has said with another during interviews, and 4) using representative quotations to optimize qualitative rigor.\textsuperscript{180}

4.3 RESULTS

Thirteen exercise participant-caregiver dyads (9 with stroke; 4 with MS) from six community centres consented to participate. One caregiver from an MS dyad withdrew prior to being interviewed. Six exercise participants and 5 caregivers were interviewed in person. Seven
exercise participants and 7 caregivers were interviewed by telephone. Five exercise participants were first-time registrants and 8 were re-registrants of the TIME™ program. Concurrent participation in other programs (e.g., chair yoga, aqua therapy) was reported by 54% of exercise participants (2 first-time registrants and 5 re-registrants). Interviews lasted approximately one hour. Characteristics of exercise participants and caregivers were summarized in Table 4.2 and 4.3, respectively. Exercise participants classified TIME™ program exercises in three items in the CHAMPS: stretching/flexibility exercises (item 34), light strength training (item 38), and general conditioning exercises (item 39).172

Two themes that addressed the study objectives emerged from the data: 1) participants perceived benefits associated with the TIME™ program; and 2) caregivers experience challenges and benefits associated with the TIME™ program. In the following sections, the type of participant (exercise participant or caregiver) and neurological condition are provided for each quotation.

4.3.1 Participants perceived benefits associated with the TIME™ program

Benefits perceived by the exercise participant as a result of the TIME™ program were described by exercise participants and caregivers. This theme was divided into two sub-themes, which have been described below.

4.3.1a Interrelated improvements in body function, activity and participation are associated with the TIME™ program

Exercise participants and caregivers agreed that participants with stroke and MS experienced a range of health improvements in body function, activity and participation in
meaningful life events following involvement in the TIME™ program and these improvements were interrelated.

Increases in muscle strength of the core and legs were recurring benefits perceived by approximately half (n=6; 46%) of the participants (i.e., 2/5 first-time registrants and 4/8 re-registrants) and some (n=2; 17%) caregivers (2/5 caregivers of first-time registrants). A common interrelationship stated by half (n=4; 50%) of re-registrants and one caregiver of a first-time registrant was the perception that these benefits led to improvements in the ability to maintain balance, walk, transfer, go up and down the stairs, and perform ADLs. One re-registrant with MS reported:

“I think it's increased my core strength and keeping some strength in my legs so I can keep walking. Getting in and out of the car, getting up off the couch. It helps you with your regular day-to-day activities because ... you're keeping your strength up.”

(Participant 4, MS)

Another re-registrant with MS described how increased leg strength and the specific physical skills learned at the TIME™ program allowed her to successfully transfer in and out of the car:

“I remember this one trainer, one volunteer, she did this exercise with us where we would lift up the leg and bring it out to the other side. Every time I go in the car, I always lift up my leg and I bring it into the car rather than my leg kind of hit the edge of the side of the car before I go in, and almost fall in ... Now I've become stronger.”

(Participant 11, MS)

Balance improvements were described by most (n=9; 69%) of the participants (i.e., 3/5 first-time registrants and 6/8 re-registrants) and a few (n=3; 25%) caregivers (i.e., 1/5 caregivers
of first-time registrants and 2/7 caregivers of re-registrants). One re-registrant with stroke described a decreased need for his walking aid as a result of his improved balance:

“I came home with a cane. I walked with a cane ... And then when I started with the TIME™ program, it got to the point where I stopped using the cane except if I was going through rough ground or snow or something like that. Then I used the cane not because I necessarily needed it but because it was a piece of security, as a safety thing that if I had a problem then there was something to help me.” (Participant 6, Stroke)

An interrelationship stated by approximately half (n=3; 38%) of the re-registrants and one caregiver of a re-registrant involved the description of how improved balance led to increased capacity to do other activities including transfers, walking, stairs, and basic/instrumental ADLs. Over half (n=7; 54%) of the participants (i.e., 3/5 first-time registrants and 4/8 re-registrants) and half (n=6; 50%) of the caregivers (i.e., 2/5 caregivers of first-time registrants and 4/7 caregivers of re-registrants) felt that the TIME™ program improved the participants’ ability to perform ADLs, with dressing being the most improved, followed by bathing, and feeding. Caregivers noted how improved balance also transferred to the performance of activities around the house:

“He can vacuum now. What else is he doing? Making the bed. He's starting to do some cooking. He takes his own shower. He can go outside the house into the garage now by himself. Like he can go up and down the stairs. There's only 3 but he can do them. And he walks outside in the yard and fixes his bird houses. And that's a direct result of having his balance and using that left arm more.” (Caregiver 6, Stroke)

Improvement in mobility as a result of the TIME™ program was described by the majority of the participants. Most (n=11; 85%) of the participants (i.e., 4/5 first-time registrants and 7/8 re-registrants) described improvement in their ability to do transfers in and out of a chair,
bed, shower, car, and on and off the toilet. Most (n=10; 77%) of the participants (i.e., 4/5 first-time registrants and 6/8 re-registrants) and most (n=8; 67%) of the caregivers (i.e., 2/5 caregivers of first-time registrants and 6/7 caregivers of re-registrants) described improvements in the participants’ walking ability, including improved walking distance. Over half (n=8; 62%) of the participants (i.e., 2/5 first-time registrants and 6/8 re-registrants) and half (n=6; 50%) of the caregivers (i.e., 2/5 caregivers of first-time registrants and 4/7 caregivers of re-registrants) described improvement in their ability to use the stairs. One participant described improvements in upper extremity function.

Over half (n=7; 54%) of the participants (i.e., 4/5 first-time registrants and 3/8 re-registrants) and over half (n=7; 58%) of the caregivers (3/5 caregivers of first-time registrants and 4/7 caregivers of re-registrants) stated that the TIME™ program affected the participants confidence in being able to do various tasks or activities. A common interrelationship stated by select (n=2; 15%) participants (1/5 first-time registrants and 1/8 re-registrants) and a few (n=3; 25%) caregivers (i.e., 1/5 caregivers of first-time registrants and 2/7 caregivers of re-registrants) involved the description of how successful performance of activities such as walking and stair ability in the TIME™ program led to increased confidence. One first-time registrant with stroke stated that the TIME™ program gave him confidence to walk longer distances without the use of his walking aid:

“But confidence in terms of taking... Like the few times I started to walk without this [referring to cane] was with TIME™...They had small distances to walk. And I'd say, okay, I'll try it without a cane. And I did it a few times. And then I did it... Like today I did more today than any other time. So yeah, it gives you confidence.” (Participant 12, Stroke)
His caregiver also agreed with the increased confidence witnessed in the participant’s mobility, and said: “*He has more confidence when he has to move. And when he does this exercise there [TIME™ program], he can see, "Oh, I can do that. Oh, I can do that."*” (Caregiver 12, Stroke)

Most (n=12; 92%) of the participants (i.e., 5/5 first-time registrants and 7/8 re-registrants) and most (n=9; 75%) of the caregivers (i.e., 3/5 caregivers of first-time registrants and 6/7 caregivers of re-registrants) described the social support they experienced through the TIME™ program, including meeting new people with similar conditions or difficulties that they could talk about or relate to. A few (n=4; 31%) participants (i.e., 2/5 first-time registrants and 2/8 re-registrants) and one caregiver of a re-registrant stated that TIME™ participants formed friendships with other TIME™ participants, and interact with these individuals outside of the TIME™ program by enjoying activities such as going out for coffee. Furthermore, approximately half (n=6; 46%) of the participants (i.e., 2/5 first-time registrants and 4/8 re-registrants) and half (n=6; 50%) of the caregivers (i.e., 1/5 caregivers of first-time registrants and 5/7 caregivers of re-registrants) described an improvement in their participation in leisure or recreational activities following the TIME™ program. One first-time registrant described an interrelationship between increased confidence and strength following the TIME™ program, which led to increased participation. This participant described improvement in his participation:

“*It let me get out to play a little bit of golf with my wife. Not very good golf but I was able to get out there. I'm able to go out and have a nice meal in a restaurant with my spouse. I'm able to go visit my kids and grandchildren. And when they come here, I can participate more with them. And if friends are coming over or if we go to friends', it's no longer...it's an expedition when you go out sometimes.*” (Participant 12, Stroke)

4.3.1b Repeated registration in the TIME™ program reinforces program benefits
Benefits observed from a single session may be further enhanced through repeated sessions. Eight participants (62%) were re-registrants of the TIME™ program, however one re-registrant completed two 6-week TIME™ program sessions equivalent to one 12-week session completed by a first-time registrant. Most (n=6; 75%) re-registrants and caregivers (n=5; 63%) noticed further improvements in strength, balance, walking, ability to use the stairs, transfers, ADL, participation in leisure or recreational activities, and reduced caregiver assistance with repeated sessions of the TIME™ program. For example, one re-registrant with stroke stated that he noticed improvements in his balance, walking and ability to do stairs following the first TIME™ program session. As a result, he participated in repeated sessions: “After the first TIME™ program, it did change. It got better. But of course the more I go, the better it gets. And that's why I keep going.” (Participant 7, Stroke)

4.3.2 Caregivers experience challenges and benefits associated with the TIME™ program

Caregivers described personal challenges and benefits associated with participation in the TIME™ program. Their primary challenge was providing transportation to the TIME™ program as described by over half (n=7; 58%) of the caregivers (i.e., 3/5 caregivers of first-time registrants and 4/7 caregivers of re-registrants). Although not described as a challenge, approximately half (n=5; 42%) of the caregivers (i.e., 4/5 caregivers of first-time registrants and 1/7 caregivers of re-registrants) engaged in the TIME™ program by providing assistance and motivation to the participant during the class. Some caregivers (i.e., 2/5 caregivers of first-time registrants) described the benefits associated with attending the TIME™ program. As they attempted to do the exercises, they became aware of their own physical fitness. One caregiver of a first-time registrant with stroke who attended the TIME™ program with her spouse described
feelings of pride and happiness as a result of helping her husband during the class. Attending the class also allowed her to do the exercises for her own physical health:

“With the exercise I do, it's better for me to be there. Because if I go, I put him there and I leave, I know he will not be able to do a lot of exercise by himself ... If I can help him, it's better for me. And I'm more proud of me. And it's great for him at the same time to help him to do that. And when he can do different things, to push something, to lift something, for him it's better. And it's better for me. I'm happy with what I do for him.”

(Caregiver 12, Stroke)

The caregiver also stated:

“I do the exercise at the same time as him. I like to do that. And for me it's great. It pushed me to do some exercise. And if I had to do that by myself, maybe I'm a little bit lazy to do that. Because I go with him, I do the exercise.” (Caregiver 12, Stroke)

Some caregivers (i.e., 2/7 caregivers of re-registrants) attended the TIME™ program because they were concerned that the participant may sustain a fall during the class. However, as these caregivers witnessed improvements in the participants, they felt that they no longer needed to attend and, instead, they used the time to perform various shopping and household related tasks. One caregiver described how she used the time while her husband attended the TIME™ program:

“Oh, everything. I do shopping, messages. I mean all kinds of things ... that just means that I don't have to go out again or we don't have to stay out longer or whatever...Like I don't go and have coffee. You know what I mean? It's all work-related within the house.”

(Caregiver 7, Stroke)
One caregiver (i.e., 1/5 caregivers of first-time registrants) also used that time to benefit their physical fitness by exercising in the gym while waiting for the participant. One caregiver of a first-time registrant with stroke said: “I just take her there. And if I'm by myself or don’t have the girls [grandchildren], I'll go do my program [personalized gym workout] while she's doing hers. So it's healthy for me.” (Caregiver 3, Stroke) One caregiver of a re-registrant was unable to engage as they were working full-time.

The majority (n=8; 67%) of the caregivers (i.e., 3/5 caregivers of first-time registrants and 5/7 caregivers of re-registrants) described the emotional benefit of the TIME™ program. It made them feel positive, happy, or optimistic as they saw the impact the program had on the participants. Moreover, caregivers felt more relaxed about what the participant was capable of doing due to observed improvements in their physical function. One caregiver of a re-registrant with MS stated that the TIME™ program made her feel happy as her daughter was participating in something that she felt was beneficial:

“I feel happy when she goes and does something that she feels is good for her. And when she comes home, she's happy ... That makes me happy and makes me more relaxed than to see her just sitting at home doing nothing.” (Caregiver 11, MS)

Over half (n=8; 62%) of the TIME™ participants (i.e., 3/5 first-time registrants and 5/8 re-registrants) and some (n=3; 25%) caregivers (i.e., 3/7 caregivers of re-registrants) felt that participants required less assistance from their caregivers in various areas (i.e., balance, mobility, ADLs) following involvement in the TIME™ program. One re-registrant with stroke stated that he required less assistance from his caregiver with ADLs: “She used to help me bathe. She was always there to do that. And to dress myself. You know, basically just everything I do every day, she's helped me with. And now it's gotten better.” (Participant 7, Stroke) The caregiver of the re-
registrant with stroke described that the TIME™ program improved her husband’s ability to walk, which made outings easier as the caregiver did not need to carry her husband’s walker:

“Well, I mean just it's so much easier to go out for dinner now because I don’t need to take the walker. He can walk with me and whatnot. So that's easier. And to go to a movie, the same thing. All these things. Anything out, he can do with me. And I don't need to be carrying a...picking up a walker and putting it in the car, and all that sort of thing. So you know, we can basically do anything like that.” (Caregiver 7, Stroke)

4.3.3 Preferences for facilitating access to CBEP-HRPs

Exercise participants and their caregivers discussed preferences for the content and timing of education about CBEP-HRPs. Table 4 summarizes exercise participants’ and caregivers’ preferences for facilitating access to CBEP-HRPs such as the TIME™ program.

4.4 DISCUSSION

This study explored the effects of a group, task-oriented CBEP-HRP on physical function, participation, caregiver assistance and caregiver health, and increased understanding of the information needs of individuals with a neurological condition and their caregivers regarding CBEP-HRPs. The two themes suggest that participants in the TIME™ program experienced interrelated improvements in body function, activities and participation that were reinforced through repeated registration in the TIME™ program, and caregivers experienced both challenges and benefits associated with the TIME™ program. In addition, enhancing access to CBEP-HRPs requires education, motivation, assistance and involvement of caregivers, and government funding.
The TIME™ program\textsuperscript{92} led participants with stroke and MS to experience benefits at the impairment (i.e., balance, strength, confidence), activity (sit-to-stand, transfers, walking endurance, stairs, ADLs and IADLs), and participation (i.e., leisure activities and social participation) levels. Systematic reviews\textsuperscript{26, 32} of task-oriented training performed in a healthcare setting by HCPs have reported similar benefits, suggesting a successful translation from the healthcare to community settings. Additionally, this qualitative study described improvements in physical and mental health in both individuals with stroke and MS. It also described the interrelationships between improvements in body function and abilities to perform activities and participate in meaningful activities witnessed in both first-time registrants and re-registrants. Similar interrelating improvements have been described by first-time registrants in a pilot study of the TIME™ program.\textsuperscript{92} Results from our study can inform the planning of larger scale quantitative studies by guiding the selection and modeling of outcomes (i.e., body function, activities, and participation) to include when evaluating the effectiveness of a group, task-oriented CBEP-HRP model.

Both participants and their caregivers noted the enhanced benefits of repeated attendance in the TIME™ program (e.g., in ADLs, IADLs, mental health, independence). These findings support the role of CBEP-HRPs in increasing access to exercise programs and providing ongoing opportunities for health maintenance and improvement. However, the extent to which providing access to CBEP-HRPs leads to long-term participation in exercise and associated benefits is still unknown.\textsuperscript{103} Further investigation is required to establish long-term benefits of exercise participation, which may aid in obtaining funding for widespread implementation of exercise programs, such as the TIME™ program.
Caregivers can benefit from their family member engaging in CBEPs like the TIME™ program. They experienced challenges related to the provision of transportation to the exercise program but they predominantly experienced benefits. Specifically, they experienced benefits including reduced caregiver assistance, increased participation, emotional benefits (i.e., happiness and optimism as they witnessed improvements in the participant), increased awareness in their own physical fitness through engagement in the TIME™ program with the participant, fulfilment in helping the participant in class, and the potential to use the time to engage in exercise or other activities while the participant was exercising. These results indicate that access to group, task-oriented CBEP-HRPs such as the TIME™ program may help mitigate negative health benefits that individuals can experience when caring for someone with physical disability. When their family member was in the TIME™ program, some caregivers did domestic or household tasks, with few caregivers using the time to engage in personally meaningful activities (i.e., exercising on their own or engaging in the TIME™ program as they felt it was benefiting both themselves and the individual with a neurological condition). Engagement in valued activities is important to caregivers to help them maintain good mental health outcomes. Results from a study evaluating restricted participation in stroke caregivers stated that the level of participation restriction may decrease over time, allowing for re-engagement in valued activities. These finding and the additional benefits associated with repeated participation in the TIME™ program suggest ongoing adaptation to stroke and the caregiving situation. For example, the “Timing It Right” framework suggests people with stroke and their caregivers experience phases of adjustment and corresponding needs. Authors suggest two phases specifically related to returning to community living and the gradual re-engagement in activities. Specifically, the implementation phase (fourth phase) includes the individual with a
neurological condition returning home and learning to live in the community, as well as beginning to engage community services and programs (i.e., CBEPs) for the first time. The adaptation phase (fifth phase) includes the individual adjusting and continuing involvement in community services (e.g., re-registration in CBEPs) and valued activities, as well as caregivers’ own engagement in meaningful activities. In the community, individuals with neurological conditions and their caregivers may benefit from access to community interventions, as this may aid in both the caregivers’ and the stroke survivors’ participation. The results from this qualitative study provide a basis for examining the need for an exercise program for caregivers that would run concurrently with the TIME™ program.

Participants in our study suggested the preferred method regarding learning about CBEP-HRPs was through discussions with HCPs. HCPs, such as primary care physicians and PTs, awareness of CBEPs is important to bridge the gap between the healthcare and community sectors, as individuals with disabilities due to a neurological condition are in frequent contact with these individuals. Moreover, the involvement of a CBEP-HRP model is valuable in increasing access to safe, feasible and beneficial exercise programs for individuals with neurological conditions, such as stroke, who are discharged from rehabilitation. As a result, HCPs may refer individuals to CBEPs at the time of discharge from in- and out-patient rehabilitation or provide education to individuals and their caregivers regarding potential health and social benefits of regular exercise participation. Marketing strategies for CBEPs are required to increase awareness and allow individuals with neurological conditions who are in the community to find and access these programs. Such tools may consist of brochures or newsletters delivered to residential homes, placed in the community or healthcare centres, care
facilities, websites, workshops, collaboration between various HCP and community services, and advocacy.\textsuperscript{184}

4.4.1 Implications

Findings from this study will enable healthcare providers to: 1) better understand the potential benefits of group, task oriented CBEP-HRPs which will help support their implementation; 2) advocate for the emergent outreach role wherein PTs offer education and training of fitness instructors working within recreation organizations; 3) better educate clients and their caregivers about the potential health and social benefits of regular exercise participation; and 4) take responsibility by referring patients to these programs at the time of discharge from in- and out-patient rehabilitation. The novel component of this study is the exploration of the effects of participation in community-based exercise on the level of caregiver assistance and health. Findings can be used to educate healthcare trainees and professionals as to the mechanisms by which community-based exercise interventions for a clinical population like stroke and MS can affect, and potentially benefit, caregiver health.

4.5 LIMITATIONS

This study had a few limitations. First, the sample size was insufficient to compare results for first-time and re-registrants of the TIME™ program and the comparison was confounded by variable program duration across sites. Second, transferability of findings to populations beyond stroke is limited, as there were few individuals in the study with MS, therefore preventing an in-depth understanding of the effects of the TIME™ program in this population.

4.6 CONCLUSIONS

People with stroke and MS and their caregivers perceive benefits from group task-oriented training within the CBEP-HRP model that are similar to those associated with delivery
of the program by healthcare professionals, suggesting successful translation from the healthcare to the community setting. Findings highlight emerging information about the impact of the TIME™ program on caregivers, inform planning for larger scale quantitative studies evaluating similar exercise programs in people with multiple neurological conditions, underline the need to assess long-term participation in exercise programs in individuals with neurological conditions and its benefits, and provide guidance for how to facilitate access to CBEPs.

4.7 ACKNOWLEDGEMENTS

This research was support by an Ontario Physiotherapy Association Kim Wolny Research Grant and a Heart and Stroke Foundation Canadian Partnership for Stroke Recovery Catalyst grant. Nancy Salbach and Jill Cameron were supported by Canadian Institutes of Health Research New Investigator and Ontario Ministry of Research and Innovation Early Researcher Awards. Ruth Barclay was supported by a Manitoba Health Council Establishment Grant.
### Table 4.1. Sample interview questions

**TIME™ Program Participant:**

1. Can you describe to what extent, if any, your participation in the TIME™ program has changed your physical function?
2. Can you describe to what extent, if any, your participation in the TIME™ program has changed how you do your usual daily activities?
3. Can you describe to what extent, if any, your participation in the TIME™ program has changed how you do household tasks on your own?
4. Can you describe to what extent, if any, your participation in the TIME™ program has changed how you were able to participate in valued activities (i.e., recreation, social, work)?
5. You’ve mentioned that your caregiver [insert name] is the person that helps you when you need help. Can you describe to what extent, if any, your participation in the TIME™ program has changed the things that he/she helps you with and how?
6. If you could provide another family with advice about exercising after being affected by [the neurological condition], what would it be?

**Caregiver:**

1. Can you describe to what extent, if any, your [family member’s] abilities to do everyday activities has changed as a result of the TIME™ program?
2. Can you describe to what extent, if any, this has changed since your [family member] participated in the TIME™ program?
3. Can you tell me about the typical activities you and your [family member] did together before the TIME™ program? (e.g., recreation)
   a. Can you describe to what extent, if any, this has changed since participating in the TIME™ program?
4. To what extent, if any, do you feel your [family member’s] participation in the TIME™ program has led to changes in your health?
   a. Can you describe to what extent, if any, your participation in valued or meaningful activities (i.e., recreation, social, work) has changed since your [family member] participated in the TIME™ program?
   b. Can you describe to what extent, if any, your mental or emotional health has changed since your [family member] participated in the TIME™ program?
   c. Can you describe to what extent, if any, your physical health has changed since your [family member] participated in the TIME™ program?
5. Can you describe to me whether you attended the TIME™ program with your [family member]?
6. If you could provide another family with advice about exercising after being affected by [the neurological condition], what would it be?
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Stroke (n=9)</th>
<th>Multiple Sclerosis (n=4)</th>
<th>All (n=13)</th>
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<tbody>
<tr>
<td><strong>Age (years), median (P_{25}-P_{75})</strong></td>
<td>69 (72-59)</td>
<td>53 (55-49)</td>
<td>59 (71-56)</td>
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<tr>
<td><strong>Men, n (%)</strong></td>
<td>6 (66)</td>
<td>1 (25)</td>
<td>7 (54)</td>
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<td><strong>Stroke type, n (%)</strong></td>
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</tr>
<tr>
<td>Both</td>
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<tr>
<td>Not reported</td>
<td>3 (33)</td>
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<td><strong>Side of cerebral lesion, n (%)</strong></td>
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</tr>
<tr>
<td>Right</td>
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<td></td>
</tr>
<tr>
<td>Left</td>
<td>2 (22)</td>
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<td></td>
</tr>
<tr>
<td>Both</td>
<td>1 (11)</td>
<td></td>
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<tr>
<td><strong>Time post-stroke (years), median (P_{25}-P_{75})</strong></td>
<td>4 (2-5)</td>
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<td><strong>TIME™ program first-time registrant, n (%)</strong></td>
<td>5 (38)</td>
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<td>10 weeks program</td>
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<td><strong>TIME™ program re-registrant, n (%)</strong></td>
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<td>2 sessions (6-week program n=1; 10-week program n=2)</td>
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<td>3 sessions (11-week program n=1)</td>
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<td>4+ sessions (6-week program n=3; 10-week program n=1)</td>
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<td><strong>Concurrent participation in other exercise programs, n (%)</strong></td>
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<tr>
<td>Yes</td>
<td>7 (54)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>6 (46)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Barthel Index (0-100), median (P_{25}-P_{75})</strong></td>
<td>75 (65-90)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CHAMPS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking (minutes/week), median (P_{25}-P_{75})</td>
<td>30 (0-105)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate-intensity PA (minutes/week), median (P_{25}-P_{75})</td>
<td>105 (105-210)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vigorous-intensity PA (minutes/week), median (P_{25}-P_{75})</td>
<td>0 (0-0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total participation (hours/week), median (P_{25}-P_{75})</td>
<td>25 (18-31)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥150 minutes/week of MVPA, n (%)</td>
<td>5 (38)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: n, number; P_{25}, 25^{th} percentile; P_{75}, 75^{th} percentile; TIME™, Together in Movement and Exercise; SD, Standard deviation; CHAMPS, Community Health Activities
Model Program for Seniors, MVPA, moderate- to vigorous-intensity physical activity; PA, physical activity.
## Table 4.3. Caregiver characteristics (n=12)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years), median (P$<em>{25}$-P$</em>{75}$)</td>
<td>61 (56-69)</td>
</tr>
<tr>
<td>Men, n (%)</td>
<td>5 (42)</td>
</tr>
<tr>
<td>Relationship to individual with neurological condition, n (%)</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>10 (83)</td>
</tr>
<tr>
<td>Child</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Parent</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Employment status, n (%)</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>6 (46)</td>
</tr>
<tr>
<td>Working full-time</td>
<td>3 (25)</td>
</tr>
<tr>
<td>Stopped working to provide care</td>
<td>2 (15)</td>
</tr>
<tr>
<td>Not applicable (child caregiver)</td>
<td>1 (8)</td>
</tr>
<tr>
<td>CAS (0-102)$^\dagger$ median (P$<em>{25}$-P$</em>{75}$)</td>
<td>47 (36-64)</td>
</tr>
<tr>
<td>Household responsibilities, median (P$<em>{25}$-P$</em>{75}$)</td>
<td>6 (6-6)</td>
</tr>
<tr>
<td>Transportation, median (P$<em>{25}$-P$</em>{75}$)</td>
<td>6 (5-6)</td>
</tr>
<tr>
<td>Managing behaviour problems, median (P$<em>{25}$-P$</em>{75}$)</td>
<td>5 (3-6)</td>
</tr>
<tr>
<td>Banking/financial, median (P$<em>{25}$-P$</em>{75}$)</td>
<td>5 (2-6)</td>
</tr>
<tr>
<td>Giving medication or assisting with treatment, median (P$<em>{25}$-P$</em>{75}$)</td>
<td>5 (1-6)</td>
</tr>
<tr>
<td>Communication with HCP, median (P$<em>{25}$-P$</em>{75}$)</td>
<td>5 (2-6)</td>
</tr>
<tr>
<td>Managing services and resources, median (P$<em>{25}$-P$</em>{75}$)</td>
<td>5 (2-6)</td>
</tr>
<tr>
<td>Managing emotional changes, median (P$<em>{25}$-P$</em>{75}$)</td>
<td>5 (3-5)</td>
</tr>
</tbody>
</table>

Abbreviations: n, number; P$_{25}$, 25$^{th}$ percentile; P$_{75}$, 75$^{th}$ percentile.

$^\dagger$The items with the highest amount of assistance required were reported.
Table 4.4. Preferences for facilitating access to the TIME™ program as described by participants and their caregivers

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Preference</th>
</tr>
</thead>
</table>
| Method for providing education about CBEPP-HRP | • Discussion with HCPs (i.e., doctors and PTs)  
• Brochure  
• Website |
| Timing of education                    | • At the time of discharge home or during outpatient rehabilitation |
| Type of information                    | • Fee  
• Who the program is for (i.e., program eligibility)  
• Contact information  
• Program location |
| Facilitating role of caregivers        | • Encouraging participants to get out and exercise and to be supportive  
• Helping to look for exercise programs for the participant  
• Attending exercise with participants (it is a motivator and allows caregivers to help the participant with home exercises) |
| Encouragement for people with neurological conditions | • Perseverance and not giving up  
• Keep moving and exercising rather than being sedentary  
• Exercise in the community as it strengthens muscles, involves socialization, has a mental/emotional impact (i.e., increasing confidence) |
| Program cost                           | • Government funding preferred as cost is a limiting factor to participation |

Abbreviations: PTs, physical therapists; HCPs, healthcare professionals.
CHAPTER FIVE

SUMMARY AND CONCLUSION
5.1 Summary and Conclusion

The overall objectives of this thesis were to identify gaps in current knowledge about group, task-oriented CBEP-HRP identified in the scoping review and to address select gaps by exploring the effects of a group, task-oriented CBEP-HRP on physical function, participation, caregiver assistance and caregiver health, as well as attempting to understand the information needs required by individuals with a neurological condition and their caregivers regarding CBEP-HRPs. The CBEP-HRP model is a safe and effective model in facilitating access to exercise programs in the community for individuals with disabilities as a result of neurological conditions. Key themes that emerged from the qualitative study included participants in the TIME™ program experiencing interrelated improvements in body function, activities and participation, and caregivers experiencing both challenges and benefits. Moreover, enhancing access to CBEP-HRPs requires education, perseverance, assistance and involvement of caregivers, and government funding. Interestingly, the ICF framework fit well with the results of the qualitative study, as it identified improvements in body function, including balance, strength, and confidence, activities, including walking ability, stairs, transfers, and ADLs, participation, including social participation and the ability to participate in recreational or leisurely activities, and environmental factors, including reduced caregiver assistance. Additionally, using the ICF framework helped to classify outcomes of studies included in the scoping review in a meaningful way and to highlight the interrelationships observed in the qualitative study related to the ICF domains of body function, activities, and participation.179

The findings of the qualitative study help to address some of the gaps in the literature identified in the scoping review, including the lack of qualitative studies examining a CBEP-HRP and evaluating outcomes such as physical function, participation in meaningful activities,
caregiver assistance and caregiver health. Outcomes such as physical function (i.e., balance, mobility, ADL function) are particularly important to examine as CBEP-HRPs have the potential to improve physical function, impacting activities and participation in meaningful roles, as well as impacting caregivers by resulting in reduced assistance and improved health. The findings from this study will inform the education of people with neurological conditions, caregivers, HCPs and policymakers about the benefits of exercise participation and the need for development of exercise programs in the community for individuals with disabilities as a result of neurological conditions.

5.2 Future Research

The thesis identified key considerations for future research and program development, including: 1) creating group, task-oriented CBEP-HRPs (as task-oriented training is beneficial in improving balance and walking capacity, group training format is beneficial in enabling social support and increasing confidence and self-efficacy, implementation of task-oriented training in the community setting is feasible as it consists of functional activities applicable to daily life); 2) informing planning for larger scale quantitative studies evaluating exercise programs with multiple neurological conditions; 3) evaluating outcomes such as body function, activities, and participation when assessing the impact of the CBEP-HRPs; 4) assessing long-term participation in exercise programs in individuals with neurological conditions and its benefits and impact on caregivers; 5) providing guidance on how to facilitate access to CBEP-HRPs; and 6) enhancing programs to meet the exercise needs of caregivers.


(75) Cameron JI, Gignac MAM. "Timing It Right": a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Educ Couns.* 2008;70:305-314.


(143) French E, Reunikka K, Macleod A. Fitness instructor training programme: Community-based exercise for people living with stroke. Thunder Bay Regional Health Sciences
Centre.


Appendix A. Search strategy: MEDLINE (OVID)

Brain diseases

AND

Spinal cord diseases

AND

(communit* adj7 exercis*)

OR

Community health centres

OR

Community health services

OR

Community networks

OR

Leisure centre*

OR

Leisure center*

OR

Recreation centre*
OR

Recreation center*

OR

Fitness centre*

OR

Fitness center*

OR

Exercise centre*

OR

Exercise center*

OR

Gym

OR

Gymnasium*

AND

Exercise therapy

OR
Train OR training

OR

Exercis*

OR

Class OR classes

OR

Group exercise

AND

Over 18

OR

(exp child/ or exp infant/) not ((exp child/ or exp infant/) and (adolescent/ or exp adult/))
Appendix B: Ethics Approval from the University of Toronto

May 29, 2014

Dr. Nancy Salbach  Ms. Saira Merai
DEPT OF PHYSICAL THERAPY  DEPT OF PHYSICAL THERAPY
FACULTY OF MEDICINE  FACULTY OF MEDICINE

Dear Dr. Salbach and Ms. Saira Merai,

Re: Your research protocol entitled, “Exploring the impact of a community-based, task-oriented exercise program on physical function, participation and caregiver health among people with stroke-related balance and mobility limitations and their caregivers”

We are writing to advise you that the Health Sciences Research Ethics Board (REB) has granted approval to the above-named research protocol under the REB’s delegated review process. Your protocol has been approved for a period of one year and ongoing research under this protocol must be renewed prior to the expiry date.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events in the research should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your current ethics approval. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry.

If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

[Signature]
Appendix C: Informed Consent for the Exercise Participants

Title of Study: Exploring the Impact of a Community-Based Exercise Program on Physical Function, Participation and Caregiver Health among People with Balance and Mobility Limitations as a Result of Neurological Conditions and their Caregivers

Student Researcher:
Saira Merali  MSc Student in Rehabilitation Science at the University of Toronto

Supervisors:
Dr. Nancy Salbach  Associate Professor, Department of Physical Therapy and Rehabilitation Sciences Institute, University of Toronto, nancy.salbach@utoronto.ca

Dr. Jill Cameron  Associate Professor, Department of Occupational Science and Occupational Therapy and Rehabilitation Sciences Institute, University of Toronto, jill.cameron@utoronto.ca

Dr. Ruth Barclay  Assistant Professor, Department of Physical Therapy, School of Medical Rehabilitation, University of Manitoba, Ruth.Barclay@umanitoba.ca

Background and Purpose of the Study:
Physical activity and exercise are beneficial for everyone. The Canadian Physical Activity Guidelines for older adults states that people with physical disabilities should participate in balance and mobility programs. Community-based exercise programs are needed so people with a neurological condition can exercise safely and maintain or improve their balance, mobility, and fitness. However, little is known about the effects of community-based exercise programs delivered by recreation providers trained by physical therapists on participation in people with neurological conditions or caregiver health in Canada. Therefore, the objectives of this study are to explore the perceptions of people with a neurological condition and their caregivers of the effects of functional group exercise programs in the community on physical function (balance, walking, activities of daily living), participation in meaningful roles (social, occupational, recreational), caregiver assistance and caregiver health.

Who is invited to participate in this study?
I am inviting 12 individuals with a neurological condition who have balance and walking problems and are participating in an exercise program in the community and their caregivers (thus, 12 caregivers) to participate in this study. The individuals with a neurological condition should be registered for the TIME™ program, should have balance and walking problems as a result of a neurological condition, should be adults over the age of 18, should be able to speak and read English, and should have a caregiver (who is an unpaid person that helps the individual with a neurological condition to live independently at home and provide support and assistance at least once a week).

What does participation in this study involve?
I am inviting you to participate in an interview and to complete a questionnaire after you complete the exercise program. The interview will last approximately one hour and will be scheduled at a time and place of your convenience. The interview can take place in person in your home, or at the community centre, or by telephone. The interview will be audiorecorded and transcribed word for word. During the interview, I will ask you about your opinions and experiences with neurological conditions and exercise programs in the community. I will also ask you about your caregiver and the assistance your caregiver provides you with. At the end of the interview, I will ask you to complete a study questionnaire which will take up to 30 minutes. I will ask you questions to obtain information about sociodemographics and about your neurological condition. I will also ask you about your ability to perform daily activities such as dressing and walking, and about how much time you spend in different leisure and physical activities. It will take you one hour and 30 minutes to complete the interview and the questionnaire.

**Conditions for Participating:**
Your participation in this study is voluntary. You may withdraw at any point in time from this study without any negative consequences. If you cannot complete the interview or choose to withdraw from this study after completion of the interview, data that has been collected up until that time will be used unless you specify that you would not like it included. It will then be deleted.

**Potential Risks:**
There are no foreseeable risks or immediate or direct benefits to participating in this study.

**Potential Benefits:**
The information gained, however, will help inform the education of people with neurological conditions and caregivers, as well as health care professionals and policy-makers, about the benefits of exercise participation and the need for development of exercise programs in the community for people with balance and mobility limitations related to a neurological condition.

**Privacy and Confidentiality:**
Information collected during the interview will remain confidential. Each participant in the study will be assigned an identification code and this code will be the only identifying mark on the audiotape and transcription. Only the student researcher, supervisors and co-investigator will have access to the accompanying codebook. Audio files will be stored in a secure server and will be destroyed after transcription. Transcripts will be placed under lock and key in a filing cabinet at the University of Toronto and will be destroyed after 10 years.

When reporting the results for this study in the research paper, general themes from the interviews are highlighted and quotes are used to illustrate a theme. Any quotes containing potential identifying information will not be used.

Upon completion of the study, a 1-page summary of the results will be provided to the participants of the study if desired.

**Compensation:**
You will be provided with a $25 compensation for your participation in the study. If the interview is conducted in person outside of the home, we will provide compensation for the cost of travel and/or parking to and from the interview up to a maximum of $15.00 per individual.

Contact Information:
If you require any additional information regarding this study, or would like a 1-page summary of the study findings (by mail or email), please contact the student researcher at:
Saira Merali
500 University Ave.,
Toronto, ON M5G 1V7 Canada
Lab Tel #: 416-946-7579
saira.merali@mail.utoronto.ca

If you have any questions about your rights as a research participant, please contact the Office of Research Ethics at ethics.review@utoronto.ca or 416-946-3273.

Copy of informed consent for participant:
This consent form is provided for your records and interest, as verbal consent will be audio-recorded prior to the beginning of the interview.

By signing below, I am indicating that I have read and understood the above information and have had the opportunity to ask questions about my involvement in the research.

Date: ____________________________________________________________________
Time of consent: __________________________________________________________
Name of participant: _______________________________________________________
Signature: ________________________________________________________________
Telephone: _______________________________________________________________
Email: ___________________________________________________________________

To be signed by researcher:

Signature: ___________________________ Date: ___________________________
Appendix D: Informed Consent for the Caregivers

**Title of Study:** Exploring the Impact of a Community-Based Exercise Program on Physical Function, Participation and Caregiver Health among People with Balance and Mobility Limitations as a Result of Neurological Conditions and their Caregivers

**Student Researcher:**
Saira Merali  MSc Student in Rehabilitation Science at the University of Toronto

**Supervisors:**
Dr. Nancy Salbach  Associate Professor, Department of Physical Therapy and Rehabilitation Sciences Institute, University of Toronto, nancy.salbach@utoronto.ca

Dr. Jill Cameron  Associate Professor, Department of Occupational Science and Occupational Therapy and Rehabilitation Sciences Institute, University of Toronto, jill.cameron@utoronto.ca

Dr. Ruth Barclay  Assistant Professor, Department of Physical Therapy, School of Medical Rehabilitation, University of Manitoba, Ruth.Barclay@umanitoba.ca

**Background and Purpose of the Study:**
Physical activity and exercise are beneficial for everyone. The Canadian Physical Activity Guidelines for older adults states that people with physical disabilities should participate in balance and mobility programs. Community-based exercise programs are needed so people with a neurological condition can exercise safely and maintain or improve their balance, mobility, and fitness. However, little is known about the effects of community-based exercise programs delivered by recreation providers trained by physical therapists on participation in people with neurological conditions or caregiver health in Canada. Therefore, the objectives of this study are to explore the perceptions of people with a neurological condition and their caregivers of the effects of functional group exercise programs in the community on physical function (balance, walking, activities of daily living), participation in meaningful roles (social, occupational, recreational), caregiver assistance and caregiver health.

**Who is invited to participate in this study?**
I am inviting 12 individuals with a neurological condition who have balance and walking problems and who are participating in an exercise program in the community and their caregivers (thus, 12 caregivers) to participate in this study. A caregiver is defined as an unpaid person that helps the individual with a neurological condition to live independently at home and provide support and assistance at least once a week. The caregivers should be frequently in contact with the individuals with a neurological condition (on a weekly basis at minimum), adults over the age of 18, and are able to speak and read English.

**What does participation in this study involve?**
I am inviting you to participate in an interview and to complete a questionnaire after you complete the exercise program. The interview will last approximately one hour and will be
scheduled at a time and place of your convenience. The interview can take place in person in
your home, or at the community centre, or by telephone. The interview will be audiorecorded
and transcribed word for word. During the interview, I will ask you about your opinions and
experiences with neurological conditions and exercise programs in the community, as well as the
assistance you provide and your health. At the end of the interview, I will ask you to complete a
study questionnaire which will take up to 30 minutes. I will ask you questions to obtain
information about sociodemographics. I will also ask you about the assistance you provide the
individual with a neurological condition. It will take you one hour and 30 minutes to complete
the interview and the questionnaire.

Conditions for Participating:
Your participation in this study is voluntary. You may withdraw at any point in time from this
study without any negative consequences. If you cannot complete the interview or choose to
withdraw from this study after completion of the interview, data that has been collected up until
that time will be used unless you specify that you would not like it included. It will then be
deleted.

Potential Risks:
There are no foreseeable risks or immediate or direct benefits to participating in this study.

Potential Benefits:
The information gained, however, will help inform the education of people with neurological
conditions and caregivers, as well as health care professionals and policy-makers, about the
benefits of exercise participation and the need for development of exercise programs in the
community for people with balance and mobility limitations related to a neurological condition.

Privacy and Confidentiality:
Information collected during the interview will remain confidential. Each participant in the study
will be assigned an identification code and this code will be the only identifying mark on the
audiotape and transcription. Only the student researcher, supervisors and co-investigator will
have access to the accompanying codebook. Audio files will be stored in a secure server and will
be destroyed after transcription. Transcripts will be placed under lock and key in a filing cabinet
at the University of Toronto and will be destroyed after 10 years.

When reporting the results for this study in the research paper, general themes from the
interviews are highlighted and quotes are used to illustrate a theme. Any quotes containing
potential identifying information will not be used.

Upon completion of the study, a 1-page summary of the results will be provided to the
participants of the study if desired.

Compensation:
You will be provided with a $25 compensation for your participation in the study. If the
interview is conducted in person outside of the home, we will provide compensation for the cost
of travel and/or parking to and from the interview up to a maximum of $15.00 per individual.
Contact Information:
If you require any additional information regarding this study, or would like a 1-page summary of the study findings (by mail or email), please contact the student researcher at:
Saira Merali
500 University Ave.,
Toronto, ON M5G 1V7 Canada
Lab Tel #: 416-946-7579
saira.merali@mail.utoronto.ca

If you have any questions about your rights as a research participant, please contact the Office of Research Ethics at ethics.review@utoronto.ca or 416-946-3273.

Copy of informed consent for participant:
This consent form is provided for your records and interest, as verbal consent will be audio-recorded prior to the beginning of the interview.

By signing below, I am indicating that I have read and understood the above information and have had the opportunity to ask questions about my involvement in the research.

Date: ____________________________________________________________________
Time of consent: _________________________________________________________
Name of participant: _____________________________________________________
Signature: _______________________________________________________________
Telephone: _________________________________
Email: ___________________________________________________________________

To be signed by researcher:

Signature: _______________________________ Date: ____________________________
Appendix E: Informed Consent for Caregivers Under Age of 18 Years

Title of Study: Exploring the Impact of a Community-Based Exercise Program on Physical Function, Participation and Caregiver Health among People with Balance and Mobility Limitations as a Result of Neurological Conditions and their Caregivers

Student Researcher:
Saira Merali MSc Student in Rehabilitation Science at the University of Toronto

Supervisors:
Dr. Nancy Salbach Associate Professor, Department of Physical Therapy and Rehabilitation Sciences Institute, University of Toronto, nancy.salbach@utoronto.ca
Dr. Jill Cameron Associate Professor, Department of Occupational Science and Occupational Therapy and Rehabilitation Sciences Institute, University of Toronto, jill.cameron@utoronto.ca
Dr. Ruth Barclay Assistant Professor, Department of Physical Therapy, School of Medical Rehabilitation, University of Manitoba, Ruth.Barclay@umanitoba.ca

Background and Purpose of the Study:
Physical activity and exercise are good for everyone. The Canadian Physical Activity Guidelines for older adults says that people with physical disabilities should participate in balance and mobility programs. Community-based exercise programs are needed so people with a neurological condition can exercise safely and maintain or improve their balance, mobility, and fitness. However, little is known about the effects of community-based exercise programs delivered by recreation providers trained by physical therapists on participation in people with a neurological condition or caregiver health in Canada. Therefore, the objectives of this study are to explore the views of people with a neurological condition and their caregivers of the effects of functional group exercise programs in the community on physical function (balance, walking, activities of daily living), participation in meaningful roles (social, occupational, recreational), caregiver assistance and caregiver health.

Who is invited to participate in this study?
I am inviting 12 individuals with a neurological condition who have balance and walking problems and who are participating in an exercise program in the community and their caregivers (thus, 12 caregivers) to participate in this study. A caregiver is defined as an unpaid person that helps the individual with a neurological condition to live independently at home and provide support and assistance at least once a week. The caregivers should be frequently in contact with the individuals with a neurological condition (on a weekly basis at minimum), and are able to speak and read English.

What does participation in this study involve?
I am inviting you to participate in an interview and to complete a questionnaire. The interview will last roughly one hour and will be at a time and place of your convenience. The interview can
take place in person in your home, or at the community centre, or by telephone. The interview will be audiorecorded and transcribed word for word. During the interview, I will ask you about your opinions and experiences with a neurological condition and exercise programs in the community, as well as the help you provide and your health. At the end of the interview, I will ask you to finish a study questionnaire which will take up to 30 minutes. I will ask you questions to obtain more information about you. I will also ask you about the help you provide the person with a neurological condition. It will take you one hour and 30 minutes to complete the interview and the questionnaire.

**Conditions for Participating:**
Your participation in this study is voluntary. You may withdraw at any point in time from this study without any bad consequences. If you cannot finish the interview or choose to leave from this study after finishing the interview, data that has been collected up until that time will be used unless you say that you would not like it included. It will then be deleted.

**Potential Risks:**
There are no predictable risks or immediate or direct benefits to participating in this study.

**Potential Benefits:**
The information gained will help inform the education of people with neurological conditions and caregivers, as well as healthcare professionals and policy-makers, about the benefits of exercise and the need for creating exercise programs in the community for people with balance and mobility problems related to a neurological condition.

**Privacy and Confidentiality:**
Information collected during the interview will remain private. Each participant in the study will be assigned an identification code and this code will be the only identifying mark on the audiotape and transcription. Only the student researcher, supervisors and co-investigator will have access to the accompanying codebook. Audio files will be stored in a secure server and will be destroyed after transcription. Transcripts will be placed under lock and key in a filing cabinet at the University of Toronto and will be destroyed after 10 years.

When reporting the results for this study in the research paper, general themes from the interviews are highlighted and quotes are used to show a theme. Any quotes with possible identifying information will not be used.

When the study is finished, a 1-page summary of the results will be given to the participants of the study if they like.

**Compensation:**
You will be given a $25 reward for your participation in the study. If the interview happens in person outside of the home, we will provide compensation for the cost of travel and/or parking to and from the interview up to a maximum of $15.00 per person.

**Contact Information:**
If you require any more information about this study, or would like a 1-page summary of the study findings (by mail or email), please contact the student researcher at:

Saira Merali  
500 University Ave.,  
Toronto, ON M5G 1V7 Canada  
Lab Tel #: 416-946-7579  
saira.merali@mail.utoronto.ca

If you have any questions about your rights as a research participant, please contact the Office of Research Ethics at ethics.review@utoronto.ca or 416-946-3273.

Copy of informed consent for participant under 18:
This consent form is provided for your records and interest, as verbal consent will be audio-recorded prior to the beginning of the interview.

By signing below, I am indicating that I have read and understood the above information and have been able to ask questions about my involvement in the research.

Date: ________________________________________________
Time of consent: ___________________________________________
Name of participant under 18: _________________________________
Signature: __________________________________________________
Telephone: __________________________________________________

To be signed by researcher:

Signature: __________________________ Date: _____________________
Appendix F: Informed Consent for Parents Whose Caregiver is Under 18 Years of Age

Title of Study: Exploring the Impact of a Community-Based Exercise Program on Physical Function, Participation and Caregiver Health among People with Balance and Mobility Limitations as a Result of Neurological Conditions and their Caregivers

Student Researcher:
Saira Merali  MSc Student in Rehabilitation Science at the University of Toronto

Supervisors:
Dr. Nancy Salbach  Associate Professor, Department of Physical Therapy and Rehabilitation Sciences Institute, University of Toronto, nancy.salbach@utoronto.ca

Dr. Jill Cameron  Associate Professor, Department of Occupational Science and Occupational Therapy and Rehabilitation Sciences Institute, University of Toronto, jill.cameron@utoronto.ca

Dr. Ruth Barclay  Assistant Professor, Department of Physical Therapy, School of Medical Rehabilitation, University of Manitoba, Ruth.Barclay@umanitoba.ca

Background and Purpose of the Study:
Physical activity and exercise are beneficial for everyone. The Canadian Physical Activity Guidelines for older adults states that people with physical disabilities should participate in balance and mobility programs. Community-based exercise programs are needed so people with a neurological condition can exercise safely and maintain or improve their balance, mobility, and fitness. However, little is known about the effects of community-based exercise programs delivered by recreation providers trained by physical therapists on participation in people with a neurological condition or caregiver health in Canada. Therefore, the objectives of this study are to explore the perceptions of people with a neurological condition and their caregivers of the effects of functional group exercise programs in the community on physical function (balance, walking, activities of daily living), participation in meaningful roles (social, occupational, recreational), caregiver assistance and caregiver health.

Who is invited to participate in this study?
I am inviting 12 individuals with a neurological condition who have balance and walking problems and who are participating in an exercise program in the community and their caregivers (thus, 12 caregivers) to participate in this study. A caregiver is defined as an unpaid person that helps the individual with a neurological condition to live independently at home and provide support and assistance at least once a week The caregivers should be frequently in contact with
the individuals with a neurological condition (on a weekly basis at minimum), and are able to speak and read English.

**What does participation in this study involve?**
I am inviting your child to participate in an interview and to complete a questionnaire after you complete the exercise program. The interview will last approximately one hour and will be scheduled at a time and place of your convenience. The interview can take place in person in your home, or at the community centre, or by telephone. The interview will be audiorecorded and transcribed word for word. During the interview, I will ask your child about their opinions and experiences with a neurological condition and exercise programs in the community, as well as the assistance they provide and their health. At the end of the interview, I will ask them to complete a study questionnaire which will take up to 30 minutes. I will ask them questions to obtain information about sociodemographics. I will also ask them about the assistance they provide the individual with a neurological condition. It will take them one hour and 30 minutes to complete the interview and the questionnaire.

**Conditions for Participating:**
Your child’s participation in this study is voluntary. They may withdraw at any point in time from this study without any negative consequences. If they cannot complete the interview or choose to withdraw from this study after completion of the interview, data that has been collected up until that time will be used unless you specify that you would not like it included. It will then be deleted.

**Potential Risks:**
There are no foreseeable risks or immediate or direct benefits to participating in this study.

**Potential Benefits:**
The information gained, however, will help inform the education of people with neurological conditions and caregivers, as well as health care professionals and policy-makers, about the benefits of exercise participation and the need for development of exercise programs in the community for people with balance and mobility limitations related to a neurological condition.

**Privacy and Confidentiality:**
Information collected during the interview will remain confidential. Each participant in the study will be assigned an identification code and this code will be the only identifying mark on the audiotape and transcription. Only the student researcher, supervisors and co-investigator will have access to the accompanying codebook. Audio files will be stored in a secure server and will be destroyed after transcription. Transcripts will be placed under lock and key in a filing cabinet at the University of Toronto and will be destroyed after 10 years.
When reporting the results for this study in the research paper, general themes from the interviews are highlighted and quotes are used to illustrate a theme. Any quotes containing potential identifying information will not be used.

Upon completion of the study, a 1-page summary of the results will be provided to the participants of the study if desired.

**Compensation:**
Your child will be provided with a $25 compensation for their participation in the study. If the interview is conducted in person outside of the home, we will provide compensation for the cost of travel and/or parking to and from the interview up to a maximum of $15.00 per individual.

**Contact Information:**
If you require any additional information regarding this study, or would like a 1-page summary of the study findings (by mail or email), please contact the student researcher at:

Saira Merali  
500 University Ave.,  
Toronto, ON M5G 1V7 Canada  
Lab Tel #: 416-946-7579  
saira.merali@mail.utoronto.ca

If you have any questions about your rights as a research participant, please contact the Office of Research Ethics at ethics.review@utoronto.ca or 416-946-3273.

Copy of informed consent for participant’s parent:
This consent form is provided for your records and interest, as verbal consent will be audio-recorded prior to the beginning of the interview.

**By signing below, I am indicating that I have read and understood the above information and have had the opportunity to ask questions about my child’s involvement in the research.**

Date: ________________________________
Name of parent: ________________________________
Signature: ________________________________
Telephone: ________________________________
Email: ________________________________

To be signed by researcher:
Appendix G: Interview Guide for Participants and Socio-demographic/Clinical Questionnaire (i.e., Barthel Index and Community Health Activities Model Program for Seniors)

Thank you for agreeing to take part in this interview. We will be speaking about your opinions and experiences with neurological conditions and exercise programs in the community. Your insights and opinions will be very helpful to us. The information you provide will inform the education of people with a neurological condition and their caregivers, as well as healthcare professionals and policy makers, about the benefits of exercise participation and the need for development of exercise programs in the community.

The information gained from this interview will be kept strictly confidential.

This interview will last approximately one hour and it will be audiorecorded.

Before we begin this interview, do you have any questions?

Ice Breaker:
1) First, I would like you to tell me about your neurological condition and what happened?
   a. Can you describe to me what kind of care you received?
      i. What hospitals were you admitted to and for how long?
2) What impact did [the neurological condition] have on you?
   a. How did [the neurological condition] affect you physically?
   b. How did [the neurological condition] affect you emotionally or your memory?
   c. How did [the neurological condition] affect your ability to speak and understand language?
3) When did you start thinking that you wanted to exercise once you returned home?
4) How important is exercising to you and why?

Discovering/Choosing TIME™:
5) How did you find out about the TIME™ program?
   a. By what means? (e.g., Internet, hospital) When?
6) Why did you choose this program? What did you like about the TIME™ program?
7) Did you consider other exercise programs?

Secondary Objective (Primary objectives below):
8) Looking back, what would have been the ideal way for you to find out about community-based exercise programs like the TIME™ program?
   b. When would you have liked to receive information about community-based exercise programs? (E.g., acute care, rehab, at time of discharge home)
i. When would you say would be the best time to get that information?
c. What information would you have liked to receive?
d. In what manner would you have liked to receive the information?
i. E.g., brochure, website, or discussion with a healthcare professional?
e. Who would you like to give you information?

First-Time or Re-Registrant:
9) Is this your first time participating in the TIME™ program? Or are you a re-registrant?
   a. If re-registrant - In this [facility name] facility, how many times have you participated in the TIME™ program previously, and why?
      i. What was the duration of sessions?
   b. Have you gone elsewhere for the TIME™ program?
      i. What other exercise facilities have you gone to for the TIME™ program?
      ii. How long? What was the duration of sessions?
   c. Why did you choose this program again?
   d. What did you expect or plan on gaining from participating in a community-based exercise program?
10) Besides the TIME™ program, did you participate in other exercise programs?
   a. What programs?
   b. When did you start those programs?
   c. Why did you do those programs?
   d. What did the TIME™ program offer that the other programs didn’t offer?

Physical Function Before and After:
Now I am going to ask you about your physical function.
11) Can you describe to what extent, if any, has your participation in the TIME™ program changed your physical function?
   a. Are there any things that you are able to do now that you were not able to do before? Are there any things that you can do better?
   b. How is your balance?
      i. Which exercise station(s) helped you the most?
   c. How is your walking ability?
      i. Which exercise station(s) helped you the most?
   d. How is your ability to use stairs?
      i. Which exercise station(s) helped you the most?
12) For re-registrants - Did your level of ability change after the first time in the TIME™ program?
   a. What changes have you noticed given that you’ve participated multiple times?
      Was there progressive change?

ADL Functions Before and After:
Now I am going to ask you about your ability to perform basic and more instrumental self-care tasks.
13) Can you describe to what extent, if any, has your participation in the TIME™ program changed how you do your usual daily activities?
   a. How is your ability to go in/out of the car/bed/chair/shower/tub/toilet?
   b. How is your ability to bathe?
   c. How is your ability to dress?
   d. How is your ability to feed?

14) For re-registrant - How did participation in the TIME™ program multiple times impact your abilities to do everyday activities?

Now I’d like to ask you about some things that we all need to do as part of our daily lives.

15) Can you describe to what extent, if any, has your participation in the TIME™ program changed how you do household tasks on your own?
   a. How is your ability to go shopping?
   b. How is your ability to prepare your own meals?
   c. How is your ability to do your own housework?
   d. Is there anything else that has changed and how?

Participation Before and After:

Now I am going to ask you about your ability to participate in social, work, and recreation activities.

16) Can you describe to what extent, if any, has your participation in the TIME™ program changed how you were able to participate in valued activities (like recreation, social, work)?
   a. Participation in recreation? (e.g., reading, walking, gardening)
   b. Participation in social roles? (e.g., role as friend/family member)
   c. Participation in occupation/work?
   d. Emotionally?
      a. For re-registrants - Was this change after the first time in the TIME™ program?

17) How do you feel about these changes? How did they impact you and your life?

Caregiver Assistance Before and After:

18) You’ve mentioned that [your caregiver] [insert name] is the person that helps you when you need help. Can you describe to what extent, if any, has your participation in the TIME™ program changed the things that he/she helped you with and how?
   a. Are you more independent? How?
      i. Can you give me an example?
   b. Are there any areas where you need more/less assistance from him/her?
      i. Can you provide an example?
      ii. E.g., walking, stairs, bathing, dressing, feeding, housework, shopping?

19) For re-registrants - Did these changes happen after the first time completing the TIME™ program or after repeating the program multiple times?
   a. After how many 12-week sessions did you notice these changes?

Conclusion:
20) Before we end, are there any other issues you would like to talk about related to the TIME™ program?

21) If you could provide another family with advice about exercising after being affected by [the neurological condition], what would it be?
   a. What advice about community-based exercise programs would you give to individuals with [the neurological condition]?
   b. What advice about community-based exercise programs would you give to family caregivers?

This brings us to the end of your interview. I would now like to obtain some more information from you, as well as have you fill out some questionnaires.

The following section inquires about sociodemographic and clinical information.

1) What is your year of birth?
   a. ____

2) What is your gender?
   a. Male
   b. Female

3) What was the month and year when you were diagnosed with [the neurological condition]?
   a. Month ____ Year _____

4) If stroke, what was your type of stroke?
   a. Ischemic
   b. Hemorrhagic

5) If stroke, in what side of your body did the stroke cause weakness?
   a. Left
   b. Right
   c. Both

6) Do you currently use a walking aid?
   a. Yes
   b. No

7) If yes, what kind of walking aid?
   a. Walker
   b. Crutch
   c. Cane
d. Wheelchair
e. Other: _____

8) Do you have any other health conditions?
   a. Please state: _____

9) Have you participated in an exercise program other than the TIME™ program?
10) Which exercise programs have you participated in since being affected by [the neurological condition]?
   a. List them all: ______

11) If you’re a re-registrant, how many times have you participated in the TIME™ program?
   a. 2 times
   b. 3 times
   c. More than 3 times

12) Who would you consider your primary caregiver?
   a. Spouse
   b. Child
   c. Friend
   d. Other: ______

I would like to thank you very much for your time and valuable input. If you require more information, or would like a summary of the study findings, please do not hesitate to contact me at saira.merali@mail.utoronto.ca.
Appendix H: Interview Guide for Caregivers and Socio-demographic/Clinical Questionnaire (i.e., Caregiver Assistance Scale)

Thank you for agreeing to take part in this interview. We will be speaking about your opinions and experiences with neurological conditions and exercise programs in the community. Your insights and opinions will be very helpful to us. The information you provide will inform the education of people with neurological conditions and their caregivers, as well as healthcare professionals and policy makers, about the benefits of exercise participation and the need for development of exercise programs in the community.

The information gained from this interview will be kept strictly confidential.

This interview will last approximately one hour and it will be audiorecorded.

*Note for telephone interviews: obtain verbal consent after going through main areas of consent form. Say “Do I have your consent to do this interview?”*

Before we begin, do you have any questions?

**Ice Breaker:**
1) First, can you tell me about your experience when your [family member] [insert name] was affected by [the neurological condition]?  
   a. What did he/she have difficulty doing?
2) How, in any way, has your [family member’s] [the neurological condition] affected you? 
3) When did you first start thinking that your [family member] should exercise after returning home?

**Discovering/Choosing TIME™:**
4) How did you find out about the TIME™ program?  
   a. By what means? (Internet, hospital) When?
5) Why did you choose this program? What did you like about the TIME™ program?  
6) Did you consider other exercise programs?

**Secondary Objective (Primary objectives below):**
7) Looking back, what would have been the ideal way for you to find out about community-based exercise programs like the TIME™ program?  
   a. When would you have liked to receive information about community-based exercise programs? (E.g., acute care, rehab, at time of discharge home)  
      a. When would you say would be the best time to get that information?  
   b. What information would you have liked to receive?  
   c. In what manner would you have liked to receive the information?  
      i. E.g., brochure, website, or discussion with a healthcare professional?  
   d. Who would you like to give you information?

**Caregivers Perceptions of Changes in Participant’s Independence:**
I have a series of questions to ask you, but they may not all be relevant to your situation. But I’m going to ask them anyway and if you feel that that’s something you can’t comment on,
then that’s okay. To start off, I’d like to ask you about your [family member’s] ability to do everyday activities.

8) Can you describe to what extent, if any, has your [family member’s] abilities to do everyday activities changed as a result of the TIME™ program?
   a. What has changed?
      i. Everyday activities? ADL/IADL (eating, bathing, shopping, housework)
      ii. Leisure (e.g., walking, gardening) and social (relationships) activities?

9) How many times has your [family member] participated in the TIME™ program?
10) For re-registrants - Were these changes after the first time in the TIME™ program or after repetitive times participating in the TIME™ program?

Now I would like to turn the focus on you. Since your [family member] has had [the neurological condition], I would now like to know how that has affected you.

**Caregiver Perceptions of Change in Caregiver Assistance:**

11) Can you tell me about the things that you typically help your [family member] with?
   a. Can you describe to what extent, if any, has this changed since your [family member] participated in the TIME™ program?
   b. What has changed?
      i. E.g., walking, stairs, dressing, feeding, housework.

12) For re-registrants - Did these changes happen after the first time or after repetitive times participating in the TIME™ program?

**Nature of Caregiver – TIME™ Participant Relationship Before and After:**

13) Can you tell me about the typical activities you and your [family member] did together before the TIME™ program? (E.g., recreation)
   a. Can you describe to what extent, if any, has this changed since participating in the TIME™ program?

14) Is there any other way you feel that the TIME™ program has affected your [family member] that we have not discussed?

**Caregiver Participation and Health:**

15) To what extent, if any, do you feel your [family member’s] participation in the TIME™ program has led to changes in your health?
   a. Can you describe to what extent, if any, has your participation in valued or meaningful activities (e.g., recreation, social, work) changed since your [family member] participated in the TIME™ program?
   b. Can you describe to what extent, if any, has your mental or emotional health changed since your [family member] participated in the TIME™ program?
   c. Can you describe to what extent, if any, has your physical health changed since your [family member] participated in the TIME™ program?

16) For re-registrants - How has your [family member’s] participation in more than one TIME™ program affected your participation in meaningful activities? Physical health? Mental and emotional health?

**Caregiver Engagement in TIME™ Program:**

17) Can you describe to me whether you attended the TIME™ program with your [family member]?
   a. Why or why not? When did you attend?
   b. If not attending, what did you do while your [family member] was at the program?
Conclusion:
18) Before we end, are there any other issues you would like to talk about related to yourself or your [family member’s] and the TIME™ program?
19) If you could provide another family with advice about exercising after being affected by [[the neurological condition], what would it be?
   a. What advice about community-based exercise programs would you give to individuals with [the neurological condition]?
   b. What advice about community-based exercise programs would you give to family caregivers?

This brings us to the end of your interview. I would now like to obtain some more information about you, as well as have you fill out a questionnaire.

The following section inquires about sociodemographic and clinical information.
1) What is your age?
   a. _____ years old
2) What is your gender?
   a. Male
   b. Female
3) Relationship to individual with [the neurological condition]?
   a. Spouse
   b. Child
   c. Friend
   d. Other: _____
4) Do you live with the individual with [the neurological condition]?
   a. Yes
   b. No
5) How often are you in contact with the individual with [the neurological condition]?
   a. Daily basis?
   b. Weekly basis?
   c. Other: _____
6) What is your employment status?
   a. Employed? Yes/No
      i. If yes, part-time or full-time? (circle one)
7) If unemployed, what is the reason?
   a. Retirement?
   b. Home duties?
   c. Illness/disability?
   d. Caring for the individual with the neurological condition?
   e. Other: _____
8) Do you have any dependents?
   a. Children?
   b. Other: _____
9) Do you currently exercise? (At least once a week for 30 minutes)
   a. Yes
   b. No
10) If you exercise, what kind of exercise do you do?
   a. Please state: ______

11) Do you have any health conditions?
   a. Please state: ______

I would like to thank you very much for your time and valuable input. If you require more information, or would like a summary of the study findings, please do not hesitate to contact me at saira.merali@mail.utoronto.ca.
Appendix I: Study Brochure

Participating Researchers

Student Researcher
Saira Mehall (MSc Student in Rehabilitation Science, University of Toronto)

Supervisors
Dr. Nancy Saltmarsh (Associate Professor, Department of Physical Therapy, University of Toronto)
Dr. Jill Cameron (Associate Professor, Department of Occupational Science and Occupational Therapy, University of Toronto)
Dr. Ruth Baroody (Assistant Professor, Department of Physical Therapy, School of Medical Rehabilitation, University of Manitoba)

Reminder:
During the last few weeks of the TIME™ program, the student researcher will attend the class and hold an information session at the end. The information session will last approximately 30 minutes and consist of a short presentation and discussion to answer any questions you may have. A sign-up sheet will be posted to obtain your name and contact information if you are interested in participating in the study.

If you would like more information on this project, please contact

Saira Mehall
Student Researcher
500 University Ave
Toronto, ON, Canada
M5S 1V7

Tel: (416) 648-7579
Email: saira.mehall@mail.utoronto.ca

Together in Movement and Exercise (TIME™) Program

Exploring the Impact of a Community-Based Exercise Program on Physical Function, Participation, and Caregiver Health among People with a Neurological Condition and their Caregivers

Physical Therapy
UNIVERSITY OF TORONTO
Who are we?
We are a research group at the University of Toronto who are conducting a study exploring the opinions and experiences of people with a neurological condition and their caregivers about exercise programs in the community.

What is the study about?
This study is about exploring the views of people with a neurological condition and their caregivers of the effects of community exercise programs on physical ability (e.g., walking), participation (e.g., in leisure activities), caregiver assistance and caregiver health.

Who are we looking for?
We are looking for the following people for this study:
- 12 people who have had a neurological condition and have participated in the TIME™ program, and have a caregiver who is also willing to participate in the study.
- A caregiver refers to a person who is most closely involved in providing support and assistance to help the individual with a neurological condition to live independently at home.

If you are currently involved in another rehabilitation or exercise program, then you may enter the study once your program is complete.

What will we be doing?
We are inviting you and your caregiver to each participate separately in a one-on-one interview and complete a questionnaire. One interview will be conducted with the individual with a neurological condition. A separate interview will be conducted with the caregiver. Each interview will last roughly one hour and will be audiorecorded. After the interview, you will be asked to fill out a study questionnaire that will take up to 30 minutes. During the interview, the student researcher will ask you about your opinions and experiences with a neurological condition and exercise programs in the community. Specifically, you will be asked about your opinions and views after participation in the TIME™ program. The questionnaire will have questions about participation and daily activities. Caregivers will be asked about their health and the amount of assistance they provide after your completion in the TIME™ program. The questionnaire will have questions about caregiving.

Where and when will the study take place?
The interviews will take place either at the community centre where you are registered, or in the convenience of your own home, or by telephone. The time of the interview will be at your convenience and availability. The interviews for you and your caregiver can be scheduled on separate days. You will be provided with a $25 compensation for your participation in the study. There will also be compensation for travel and/or parking, to and from the interview up to a maximum of $15.00 per person for interviews held outside the home.

What will we do with the information that we will collect from you?
The information collected from you during the interview will remain confidential. Your name will be removed and you will be given an ID number. This means that any information you give us will be kept confidential and no one will be able to identify you.

When writing the results of this study, quotes from the interviews may be used. Any quotes that have information that may identify you will not be used.

How will the study findings be used?
Results from this study will be used to:
1) educate people with a neurological condition and caregivers about the benefits of community exercise programs
2) educate healthcare professionals and policy-makers about the benefits of community exercise programs
3) justify the need for creating exercise programs in the community for people with neurological conditions.
Appendix J: Recruitment Poster

TOGETHER IN MOVEMENT AND EXERCISE
(TIME™) PROGRAM

Exploring the impact of a Community-Based Exercise Program on
Physical Function, Participation, and Caregiver Health among People
with a Neurological Condition and their Caregivers

WHO ARE WE?
We are a research group at the University of Toronto conducting a study to explore the
experiences of people with a neurological condition and caregivers about exercise
programs in the community.

WHAT IS THIS STUDY ABOUT?
This study is about exploring the views of people with a neurological condition and their caregivers
about the effects of community exercise programs on physical ability (e.g., walking), participation (e.g.,
in leisure activities), caregiver assistance and caregiver health.

WHO IS ELIGIBLE TO PARTICIPATE?
- A person who has had a neurological condition and is participating in the
  TIME™ program, and has a caregiver who is also willing to participate in the
  study.
- A caregiver (a person who provides support and assistance to a person with a
  neurological condition who is participating in the TIME™ program).

WHAT WILL WE BE DOING?
- We are inviting people with a neurological condition and their caregivers to
  participate separately in a one-on-one interview and complete a questionnaire.
- Each interview will be roughly one hour.
- Where: Interviews will take place at the community centre you are registered or
  at your home, or by telephone.
- When: At your availability and preference.

IF YOU ARE INTERESTED IN PARTICIPATING OR WOULD LIKE MORE
INFORMATION, PLEASE CONTACT:

Saira Merali
Student Researcher
Tel: (416) 946-7579
Email: saira.merali@mail.utoronto.ca
Appendix K: Script to Recruit People with Neurological Conditions on Phone

Hello, my name is Saira Merali, and I am a student at the University of Toronto. We are conducting a study to explore the views of people with a neurological condition and their caregivers of the effects of exercise programs in the community on physical activity (e.g., walking), participation (e.g., in leisure activities), and caregiver health. We would like to know if you would like to participate. Your participation would involve taking part in a one-on-one interview and providing your opinions and experiences with neurological conditions and exercise programs in the community. The interview will be roughly one hour and will be scheduled at a time and place of your convenience, such as your home, or at the community centre, or by telephone. Following the interview, you will be asked to complete a study questionnaire which will take up to 30 minutes. I will ask you questions to obtain information about sociodemographics and about your neurological condition. I will also ask you about your ability to perform daily activities such as dressing and walking, and about how much time you spend in different leisure and physical activities. It will take you one hour and 30 minutes to complete the interview and the questionnaire. The goal of this research is to educate people with a neurological condition and their caregivers, as well as healthcare professionals and policy-makers, about the benefits of exercise and to justify the need for creating exercise programs in the community for people with neurological conditions.

Are you interested participating?

If yes, then review the full consent form with them, obtain verbal consent, and schedule a time and place for the interview. In person, obtained signed consent. Also, ask if you can speak to their caregivers about participating in the study.

If they need more time to consider participating, tell them that you would call back at a later date.

If no, thank them for their time, let them know that they can call or email you if they have any questions or if they re-consider their participation.

If you would like to be interviewed by telephone, may I please obtain your home address so I can mail the questionnaire that must be completed as well as for you to send me the signed consent forms? A stamped return envelope will be included.
Appendix L: Script to Recruit Caregivers on Phone

Hello, my name is Saira Merali, and I am a student at the University of Toronto. We are conducting a study to explore the views of people with a neurological condition and their caregivers of the effects of exercise programs in the community on physical activity (e.g., walking), participation (e.g., in leisure activities), and caregiver health. We would like to know if you would like to participate. As a caregiver, your participation would involve taking part in a one-on-one interview and providing your opinions and experiences about how much care you provide and about your health. The interview will be roughly one hour and will be scheduled at a time and place of your convenience, such as your home, or at the community centre, or by telephone. Following the interview, you will be asked to complete a questionnaire that will take up to 30 minutes. I will ask you questions to obtain information about sociodemographics. I will also ask you about the assistance you provide the individual with a neurological condition. It will take you approximately one hour and 30 minutes to complete the interview and the questionnaire. The goal of this research is to educate people with a neurological condition and their caregivers, as well as healthcare professionals and policy-makers, about the benefits of exercise and to justify the need for creating exercise programs in the community for people with neurological conditions.

Are you interested participating?

If yes, then review the full consent form with them, obtain verbal consent, and schedule a time and place for the interview. In person, obtained signed consent.

If they need more time to consider participating, tell them that you would call back at a later date.

If no, thank them for their time, let them know that they can call or email you if they have any questions or if they re-consider their participation.
Appendix M: Script for TIME™ Program Coordinator to Announce to Class about Study

A Master’s Student at the University of Toronto named Saira Merali is conducting a study exploring the opinions and experiences of people with neurological conditions and their caregivers about the impact of community exercise programs like the TIME™ program. The student wishes to invite dyads: people who have had a neurological condition and who also have a caregiver into the study. The student wishes to interview the person with a neurological condition and to also interview the caregiver. If you have had a neurological condition, I have already given you an envelope containing a brochure about the study and consent forms. Saira will be here after each class in the last few weeks for 30 minutes to hold an information session and answer questions. There will also be a sign-up sheet to obtain your name and contact information and your caregivers name and contact information if you and your caregiver are interested in participating in the study. Please make sure that your caregiver has agreed to participate in the study before you give their name and contact information. If you have questions about the study, you may call or email Saira. The phone number and email address are on the brochure.

Steps:

Hand out envelopes containing study brochure and consent form to individuals with a neurological condition.
Appendix N: Recruitment Script for Student Researcher to Provide a Study Overview to People with Neurological Conditions

Hello, my name is Saira Merali, and I am doing my Master’s degree at the University of Toronto in Rehabilitation Science. My interests lie in community-based exercise programs like the TIME™ program. The objectives of my study are to explore your opinions and experiences with a neurological condition about how participation in the TIME™ program has affected your health and social activities, as well as how it has impacted your family. Your participation in this study would involve taking part in a one-on-one interview that will be roughly one hour and will be at a time and place of you convenience, such as your home, or at the community centre, or by telephone. After the interview, you will be asked to complete a study questionnaire which will take up to 30 minutes. So the total time for this study will be one hour and 30 minutes. The goal of this research is to educate people with a neurological condition and their caregivers, as well as healthcare professionals and policy-makers, about the benefits of exercise and to justify the need for creating exercise programs in the community for people with neurological conditions.

Does anyone have any questions?

If you are interested in participating, please fill your name and the name of your caregiver and phone number on the sign-up sheet.

If you need more time to consider participating, you can still fill out your name and contact information and I will call you on a later date to see if you and your caregiver have made a decision.

If no, then that is perfectly fine. Thank you very much for your time. If you have any questions or if you re-consider your participation, then you may call or email me, and my contact information is on the brochure.
Appendix O: Contact Information with Resources for Study Participants

The first resource is the Heart and Stroke Foundation of Ontario, which provides a Heart & Stroke Living with Stroke program. This is a community-based support and educational program designed for stroke survivors and their caregivers to gain confidence in managing the challenges of living with stroke. In this program, you learn new skills, make new friends, and develop confidence in your ability to control your life. I will provide you with contact information so that you can find out more information if you are interested.

Heart and Stroke Foundation of Ontario
Living with Stroke – Toronto (East)
Providence Healthcare
Phone: 416-285-3666 ext. 3810
Email: info@providence.on.ca
Address: 3276 St. Clair Avenue East, Toronto, ON
Meeting details:
- Weekly two-hour meetings
- Lead by healthcare professional
- Consists of principles of self-management and interactive sessions that focus on building skills, sharing experiences and support.

The second resource is the Ontario March of Dimes-Stroke Recovery Canada, which is a national service offering post-recovery support, education and programs for stroke and acquired brain injury survivors and their family members and caregivers in Toronto. I will provide you with contact information if you would like to find out more information about the support groups and services offered.

Ontario March of Dimes
Toronto Central Stroke Recovery Chapter
Contact: Tom Rideout
Phone: 416-425-3463 ext. 7714
Email: torontocentral@srn.ca
Address: P.O. Box 22137, 10 Overlea Blvd, Toronto, ON. M4H 1A4
Meeting Details:
- This is a support group that is offered the second Tuesday of every month from 11:00-2:00 p.m.
- Exercise classes held most Tuesday evenings from 6-7 p.m. (please call for details)
- Location: Ontario March of Dimes, 10 Overlea Blvd, Toronto, ON

Toronto Care Partners Stroke Recovery Group
Contact: Tom Rideout
Phone: 416-425-3463 ext. 7714
Email: torontocentral@srn.ca
Meeting Details:
- This is a support group that only provides telephone support.

The third resource is the Parkinson Society Canada, which is a foundation dedicated to research, education, support, and advocacy on behalf of Canadians living with Parkinson’s disease since 1965.

**Parkinson Society Canada**
Contact: Marina Joseph
Phone: 1-800-565-3000 ext. 3399
Website: [www.parkinson.ca](http://www.parkinson.ca)
### Appendix P: Screening Form for Eligibility of Exercise Participants

### Screening Checklist

<table>
<thead>
<tr>
<th><strong>Inclusion Criteria</strong></th>
<th><strong>Yes or No</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis of neurological condition (self-report)</td>
<td></td>
</tr>
<tr>
<td>Age ≥ 18 years</td>
<td></td>
</tr>
<tr>
<td>Have a caregiver</td>
<td></td>
</tr>
<tr>
<td>Registered in a CBEP targeting balance and mobility limitations (requires sufficient cognitive function and physician approval)</td>
<td></td>
</tr>
<tr>
<td>able to walk a minimum of 10 meters with or without the use of an ambulatory aid</td>
<td></td>
</tr>
<tr>
<td><strong>Currently</strong> have balance and mobility deficits as a result of a neurological condition (self-report)</td>
<td></td>
</tr>
<tr>
<td>able to speak and read English</td>
<td></td>
</tr>
<tr>
<td><strong>Exclusion Criteria</strong></td>
<td></td>
</tr>
<tr>
<td>moderate to severe aphasia in the judgment of the exercise instructor</td>
<td></td>
</tr>
</tbody>
</table>
Appendix Q: Screening Form for Eligibility of Caregivers

Screening Checklist

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Yes or No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-report being frequently in contact (weekly basis at minimum) and helping the individual with a neurological condition</td>
<td></td>
</tr>
<tr>
<td>Age ≥ 18 years. If ≤ 18, parental consent obtained</td>
<td></td>
</tr>
<tr>
<td>Ability to speak and read English</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion criteria</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal support worker (paid)</td>
<td></td>
</tr>
</tbody>
</table>
Appendix R: Thank You Letter to Study Participants

December 8, 2014
For adult participants:
Dear [Mr./Ms./Mrs. last name],

For child caregiver:
Dear [first name],

Thank you for participating in our study entitled: Exploring the Impact of a Community-Based Exercise Program on Physical Function, Participation and Caregiver Health among People with Balance and Mobility Limitations as a Result of Neurological Conditions and their Caregivers. We were successfully able to recruit 12 individuals with neurological conditions and their caregiver to participate in the study.

Please find a gift card in the amount of $25 enclosed as a token of our appreciation for your participation.

Your contribution will help inform the education of people with neurological conditions and their caregivers, as well as healthcare professionals and policy makers, about the benefits of exercise participation and the need for development of exercise programs in the community.

Sincerely,

Nancy M. Salbach, PT, PhD
CIHR New Investigator in Knowledge Translation
Associate Professor, Department of Physical Therapy, Faculty of Medicine, University of Toronto
160-500 University Avenue
Toronto, ON M5G 1V7 Canada
nancy.salbach@utoronto.ca

Saira Merali, BSc, MSc Candidate
Research Assistant, Department of Physical Therapy
Graduate Student, Rehabilitation Sciences Institute, University of Toronto
500 University Ave., Room 803
Toronto, ON M5G 1V7 Canada
saira.merali@mail.utoronto.ca
Appendix S: Codebook for Qualitative Analysis

Codebook for TIME™ Participants and Caregivers

Stroke history
- Stroke_Experience (Comments about the diagnosis, occurrence, and history of stroke and the hospital experience)

MS history
- MS_Experience (Comments about the diagnosis, occurrence, and history of MS and the hospital experience)

Impact of stroke (Impact – positive or negative)
- Impact_Physical (Comments about changes in the participants physical function as a result of stroke (e.g., left or right side of body impacted, walking/mobility impacted, fatigue, balance, coordination))
- Impact_Emotional (Comments about changes in the participants emotions as a result of stroke (e.g., anxiety, stress, well-being, confidence, mood))
- Impact_Cognitive (Comments about changes in the participant’s memory (short-term, long-term) or executive function (ability to organize, problem solving) due to stroke)
- Impact_Communication (Comments about changes in the participants ability to understand or speak language as a result of stroke)
- Impact_Participation (Comments about the changes in participation as a result of stroke (e.g., employment, relationships, leisure-golf, movies, picnic, driving, volunteering, group meetings, dancing, cards, sports, instrument))
- Impact_IADL (Comments about the changes in IADL as a result of stroke (e.g., household tasks, banking, cutting grass, cooking, making coffee))
- Impact_ADL (Comments about the changes in ADL as a result of stroke (e.g., self-care such as in BI))
- Impact_Other (Other comments about the positive or negative impact of the stroke)

Impact of MS (Impact – positive or negative)
- Impact_Physical (Comments about changes in the participants physical function as a result of MS (e.g., left or right side of body impacted, walking/mobility impacted, fatigue, balance, coordination))
- Impact_Emotional (Comments about changes in the participants emotions as a result of MS (e.g., anxiety, stress, well-being, confidence, mood))
- Impact_Cognitive (Comments about changes in the participant’s memory (short-term, long-term) or executive function (ability to organize, problem solving) due to MS)
- Impact_Communication (Comments about changes in the participants ability to understand or speak language as a result of MS)
- Impact_Participation (Comments about the changes in participation as a result of MS (e.g., employment, relationships, leisure-golf, movies, picnic, driving))
- Impact_IADL (Comments about the changes in IADL as a result of MS (e.g., household tasks, banking, cutting grass, cooking, making coffee))
- Impact_ADL (Comments about the changes in ADL as a result of MS (e.g., self-care such as in BI))
  - Impact_Other (Other comments about the positive or negative impact of the MS)

Timing exercise
- Exercise_Timing (Comments about when the participant or caregiver started thinking that the participant should exercise)
- Exercise_Began (Comments about when the participant started exercising and the exercise program(s))

Exercise motivation
- Exercise_Motivation (Comments about why the participant wants to exercise and why the participant keeps exercising in general (e.g., wanting to improve, noticing improvements and changes, watching others improve))

Information
- Exercise_Who (Comments about which person or people should ideally provide the patient and/or caregiver with information about the TIME™ program)
- Exercise_How (Comments about the manner of information wanted (e.g., brochure, website, discussion with healthcare professionals))
- Exercise_What (Comments about the kind of information wanted (e.g., what program teaches, cost, who the program is for))
- Exercise_When (Comments about when the participant/caregiver wanted to receive the information)
- TIME™ program_Source (Comments about how the participant/caregiver found out about TIME™)
- TIME™ program_Target (Comments about who should be informed about TIME™)

Concurrent Physiotherapy
- Physiotherapy_When (Comments about when the participant took physio and if they took physio at the same time as the TIME™ program)
- Physiotherapy_Experience (Comments about participants experience with physio)

Concurrent Exercise Program
- Concurrent Exercise_When (Comments about exercises taken at the same time as the TIME™ program (e.g., pool therapy, chair yoga))
- Concurrent Exercise Experience (Comments about the experience with other exercises taken at the same time as the TIME™ program)

Impact (positive and negative) of TIME™ program
- TIME™ impact_Balance (Comments about the impact of TIME™ on the participant’s balance)
- TIME™ impact_Balance-stations (Comments about the exercise stations that helped the most with balance)
- TIME™ impact_Walking (Comments about the impact of TIME™ on the participant’s walking ability)
- TIME™ impact_Walking-stations (Comments about the exercise stations that helped the most with walking ability)
- TIME™ impact_Stairs (Comments about the impact of TIME™ on the participant’s stairs)
- TIME™ impact_Stairs-stations (Comments about the exercise stations that helped the most with stairs)
- TIME™ impact_Transfers (Comments about the changes in the participant’s ability to transfer as a result of the TIME™ program)
- TIME™ impact_Coordination (Comment about the changes in the participant’s coordination as a result of the TIME™ program)
- TIME™ impact_Emotional (Comments about the changes in emotion as a result of the TIME™ program (e.g., confidence, well-being, positive mood, optimism))
- TIME™ impact_Cognitive (Comments about the changes in the participant’s cognition as a result of the TIME™ program (e.g., improved memory and executive function))
- TIME™ impact_ADL (Comments about the changes in ADL as a result of the TIME™ program (e.g., bathing, dressing, feeding, transfers, shaving or personal hygiene))
- TIME™ impact_IADL (Comments about the changes in IADL as a result of the TIME™ program (e.g., shopping, cooking, housework or household tasks))
- TIME™ impact_Participation (Comments about the changes in participation as a result of the TIME™ program (e.g., social roles such as formation of friendships, recreational activities before the diagnosis, before TIME™ and after TIME™))
- TIME™ impact_Other (Other comments about the impact of TIME™ on the participant (e.g., fatigue))
- TIME™ impact_Re-registration (Comments about how many times they participated in the TIME™ program (adherence), why they chose the TIME™ program again, and the impact or changes in the level of ability after multiple TIME™ sessions)
- TIME™ impact_Caregiver (Comments about the benefits or improvements because the TIME™ participant has gotten better at something and reduces caregiver assistance (e.g., dropping soap, less assistance with stairs))

Caregiver Involvement
- Caregiver_Assistance (Comments about the assistance provided by the participant’s caregiver e.g., how the caregiver helps participant as a result of the stroke/MS (e.g., driving, shopping, laundry, banking, orienting, dressing))
- Caregiving_Impact (Comments about any positive or negative impacts of caregiving on the caregiver. Don’t make assumptions. (e.g., early retirement to care, home renovations, making plans before doing anything))
- Caregiver_Attendance (Comments about the caregiver’s attendance in TIME™)

Advice
- Advice_Individuals (Comments about the advice regarding CBEPs to individuals diagnosed with stroke/MS)
- Advice_Caregiver (Comments about the advice regarding CBEPs to family caregivers (e.g., support, pushing patients to exercise, making time to participate in CBEPs)

Miscellaneous (Comments about anything that does not fit in the above codes)

Quotes (Comments about good examples of participant quotations that could be used in the paper)
## Appendix T: Operational Definitions

<table>
<thead>
<tr>
<th>Keyword</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structure</td>
<td>A structured, instructional program of physical activity. The components of structure consist of frequency (# of classes per week), program duration (# of weeks), class duration (hours), program format (individual, group, or a combination of individual and group format), stand-alone or multi-component program (e.g., exercise and education scheme), group size, instructor to participant ratio, and the cost of participating in the exercise program</td>
</tr>
<tr>
<td>Content</td>
<td>Defined as the types of exercises conducted in the exercise program, as well as other components of the program (e.g., education)</td>
</tr>
<tr>
<td>Delivery</td>
<td>Defined as the qualifications of the person who delivered the exercise program (e.g., recreation/fitness instructor)</td>
</tr>
<tr>
<td>Setting</td>
<td>Defined as the location where the exercise program took place</td>
</tr>
<tr>
<td>Healthcare Professional</td>
<td>Defined as a physical therapist, occupational therapist, kinesiologist or other healthcare professional</td>
</tr>
</tbody>
</table>
Appendix U: Barthel Index

Name: ___________________________________        Date: _______________
Hospital: _________________________________

1. If there was no one to help you with your feeding, could you do it alone?
   (unable = 0; needs assistance = 5; fully independent = 10)    _____

2. If there was no one to help you with your personal hygiene, could you do it alone?
   (unable = 0; needs assistance = 0; fully independent = 5)    _____

3. If there was no one to help you, would you be able to bathe or shower without
   anyone present?   (unable = 0; needs assistance = 0; fully independent = 5)  _____

4. If there was no one to help you, would you be able to dress yourself?
   (unable = 0; needs assistance = 5; fully independent = 10)    _____

5. If there was no one to help you, would you be able to get to the toilet on your own?
   (unable = 0; needs assistance = 5; fully independent = 10)    _____

6. Do you have any trouble with bowel incontinence?
   (complete = 0; occasional accident = 5; complete control day and night = 10)  _____

7. Do you have any trouble with bladder control?
   (complete = 0; occasional accident = 5; complete control day and night = 10)  _____

8. Can you transfer from bed to chair independently?
   (unable = 0; needs assistance = 10; fully independent = 15)    _____

9. Can you walk 50 yards without help or supervision?
   (unable = 0; needs assistance = 10; fully independent = 15)    _____

10. Can you go up and down stairs independently?
    (unable = 0; needs assistance = 5; fully independent = 10)    _____

Evaluate only if patient is unable to walk:

11. Do you use a wheelchair?
    (unable = 0; needs assistance = 0; fully independent = 10)    _____

Total _____
Appendix V: Community Health Activities Model Program for Seniors

<table>
<thead>
<tr>
<th>In a typical week during the past 4 weeks, did you ...</th>
<th>CHAMPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Visit with friends or family (other than those you live with)?</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td>□ YES  How many TIMES a week?_____ ⇒ □ NO</td>
<td>Less than 1 hour 1-2½ hours 3-4½ hours 5-6½ hours 7-8½ hours 9 or more hours</td>
</tr>
<tr>
<td>2. Go to the senior center?</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td>□ YES  How many TIMES a week?_____ ⇒ □ NO</td>
<td>Less than 1 hour 1-2½ hours 3-4½ hours 5-6½ hours 7-8½ hours 9 or more hours</td>
</tr>
<tr>
<td>3. Do volunteer work?</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td>□ YES  How many TIMES a week?_____ ⇒ □ NO</td>
<td>Less than 1 hour 1-2½ hours 3-4½ hours 5-6½ hours 7-8½ hours 9 or more hours</td>
</tr>
<tr>
<td>4. Attend church or take part in church activities?</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td>□ YES  How many TIMES a week?_____ ⇒ □ NO</td>
<td>Less than 1 hour 1-2½ hours 3-4½ hours 5-6½ hours 7-8½ hours 9 or more hours</td>
</tr>
<tr>
<td>5. Attend other club or group meetings?</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td>□ YES  How many TIMES a week?_____ ⇒ □ NO</td>
<td>Less than 1 hour 1-2½ hours 3-4½ hours 5-6½ hours 7-8½ hours 9 or more hours</td>
</tr>
<tr>
<td>6. Use a computer?</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td>□ YES  How many TIMES a week?_____ ⇒ □ NO</td>
<td>Less than 1 hour 1-2½ hours 3-4½ hours 5-6½ hours 7-8½ hours 9 or more hours</td>
</tr>
</tbody>
</table>
### In a typical week during the past 4 weeks, did you …

<table>
<thead>
<tr>
<th>Activity</th>
<th>Yes/No</th>
<th>How Many Times a Week?</th>
<th>Yes/No</th>
<th>How Many TOTAL Hours a Week Did You Usually Do It?</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. Dance (such as square, folk, line, ballroom) (do not count aerobic dance here)?</td>
<td></td>
<td></td>
<td></td>
<td>Less than 1-2½ 1-2½ hours 3-4½ 5-6½ 7-8½ 9 or more more</td>
</tr>
<tr>
<td>□ YES How many TIMES a week?_____ →</td>
<td></td>
<td></td>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? →</td>
</tr>
<tr>
<td>8. Do woodworking, needlework, drawing, or other arts or crafts?</td>
<td>□ YES</td>
<td>How many TIMES a week?</td>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? →</td>
</tr>
<tr>
<td>□ YES How many TIMES a week?_____ →</td>
<td></td>
<td></td>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? →</td>
</tr>
<tr>
<td>9. Play golf, carrying or pulling your equipment (count walking time only)?</td>
<td>□ YES</td>
<td>How many TIMES a week?</td>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? →</td>
</tr>
<tr>
<td>□ YES How many TIMES a week?_____ →</td>
<td></td>
<td></td>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? →</td>
</tr>
<tr>
<td>10. Play golf, riding a cart (count walking time only)?</td>
<td>□ YES</td>
<td>How many TIMES a week?</td>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? →</td>
</tr>
<tr>
<td>□ YES How many TIMES a week?_____ →</td>
<td></td>
<td></td>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? →</td>
</tr>
<tr>
<td>11. Attend a concert, movie, lecture, or sport event?</td>
<td>□ YES</td>
<td>How many TIMES a week?</td>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? →</td>
</tr>
<tr>
<td>□ YES How many TIMES a week?_____ →</td>
<td></td>
<td></td>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? →</td>
</tr>
<tr>
<td>12. Play cards, bingo, or board games with other people?</td>
<td>□ YES</td>
<td>How many TIMES a week?</td>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? →</td>
</tr>
<tr>
<td>□ YES How many TIMES a week?_____ →</td>
<td></td>
<td></td>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? →</td>
</tr>
</tbody>
</table>
In a typical week during the past 4 weeks, did you …

<table>
<thead>
<tr>
<th>Activity</th>
<th>Champs</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. Shoot pool or billiards?</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td><strong>YES</strong> How many TIMES a week? _____ ➔</td>
<td>Less than 1 hour 1-2½ 3-4½ 5-6½ 7-8½ 9 or more hours</td>
</tr>
<tr>
<td><strong>NO</strong></td>
<td></td>
</tr>
<tr>
<td>14. Play singles tennis (do not count doubles)?</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td><strong>YES</strong> How many TIMES a week? _____ ➔</td>
<td>Less than 1 hour 1-2½ 3-4½ 5-6½ 7-8½ 9 or more hours</td>
</tr>
<tr>
<td><strong>NO</strong></td>
<td></td>
</tr>
<tr>
<td>15. Play doubles tennis (do not count singles)?</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td><strong>YES</strong> How many TIMES a week? _____ ➔</td>
<td>Less than 1 hour 1-2½ 3-4½ 5-6½ 7-8½ 9 or more hours</td>
</tr>
<tr>
<td><strong>NO</strong></td>
<td></td>
</tr>
<tr>
<td>16. Skate (ice, roller, in-line)?</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td><strong>YES</strong> How many TIMES a week? _____ ➔</td>
<td>Less than 1 hour 1-2½ 3-4½ 5-6½ 7-8½ 9 or more hours</td>
</tr>
<tr>
<td><strong>NO</strong></td>
<td></td>
</tr>
<tr>
<td>17. Play a musical instrument?</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td><strong>YES</strong> How many TIMES a week? _____ ➔</td>
<td>Less than 1 hour 1-2½ 3-4½ 5-6½ 7-8½ 9 or more hours</td>
</tr>
<tr>
<td><strong>NO</strong></td>
<td></td>
</tr>
<tr>
<td>18. Read?</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td><strong>YES</strong> How many TIMES a week? _____ ➔</td>
<td>Less than 1 hour 1-2½ 3-4½ 5-6½ 7-8½ 9 or more hours</td>
</tr>
<tr>
<td><strong>NO</strong></td>
<td></td>
</tr>
</tbody>
</table>
In a typical week during the past 4 weeks, did you …

<table>
<thead>
<tr>
<th>Question</th>
<th>CHAMPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. Do heavy work around the house (such as washing windows, cleaning gutters)?</td>
<td>□ YES  How many TIMES a week? _____ ➤ How many TOTAL hours a week did you usually do it? ➤ Less than 1 hour 1-2½ hours 3-4½ hours 5-6½ hours 7-8½ hours 9 or more hours</td>
</tr>
<tr>
<td>□ NO</td>
<td>□ NO</td>
</tr>
<tr>
<td>20. Do light work around the house (such as sweeping or vacuuming)?</td>
<td>□ YES  How many TIMES a week? _____ ➤ How many TOTAL hours a week did you usually do it? ➤ Less than 1 hour 1-2½ hours 3-4½ hours 5-6½ hours 7-8½ hours 9 or more hours</td>
</tr>
<tr>
<td>□ NO</td>
<td>□ NO</td>
</tr>
<tr>
<td>21. Do heavy gardening (such as spading, raking)?</td>
<td>□ YES  How many TIMES a week? _____ ➤ How many TOTAL hours a week did you usually do it? ➤ Less than 1 hour 1-2½ hours 3-4½ hours 5-6½ hours 7-8½ hours 9 or more hours</td>
</tr>
<tr>
<td>□ NO</td>
<td>□ NO</td>
</tr>
<tr>
<td>22. Do light gardening (such as watering plants)?</td>
<td>□ YES  How many TIMES a week? _____ ➤ How many TOTAL hours a week did you usually do it? ➤ Less than 1 hour 1-2½ hours 3-4½ hours 5-6½ hours 7-8½ hours 9 or more hours</td>
</tr>
<tr>
<td>□ NO</td>
<td>□ NO</td>
</tr>
<tr>
<td>23. Work on your car, truck, lawn mower, or other machinery?</td>
<td>□ YES  How many TIMES a week? _____ ➤ How many TOTAL hours a week did you usually do it? ➤ Less than 1 hour 1-2½ hours 3-4½ hours 5-6½ hours 7-8½ hours 9 or more hours</td>
</tr>
<tr>
<td>□ NO</td>
<td>□ NO</td>
</tr>
</tbody>
</table>
**Please note: For the following questions about running and walking, include use of a treadmill.**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>24. Jog or run?</td>
<td></td>
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<tr>
<td>□ YES How many TIMES a week?  ➔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ NO</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
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<td></td>
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<tr>
<td>Less than 1 hour</td>
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<td>1-2½ hours</td>
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<td>3-4½ hours</td>
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<td>7-8½ hours</td>
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<tr>
<td>9 or more</td>
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<tr>
<td>25. Walk uphill or hike uphill (count only uphill part)?</td>
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<tr>
<td>□ YES How many TIMES a week?  ➔</td>
<td></td>
<td></td>
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<tr>
<td>□ NO</td>
<td></td>
<td></td>
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<tr>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
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<tr>
<td>Less than 1 hour</td>
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<td>1-2½ hours</td>
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<td>5-6½ hours</td>
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<tr>
<td>7-8½ hours</td>
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<tr>
<td>9 or more</td>
<td></td>
<td></td>
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<tr>
<td>26. Walk fast or briskly for exercise (do not count walking leisurely or uphill)?</td>
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<td></td>
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<tr>
<td>□ YES How many TIMES a week?  ➔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ NO</td>
<td></td>
<td></td>
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<tr>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
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<td></td>
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<tr>
<td>Less than 1 hour</td>
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<td>1-2½ hours</td>
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<td>3-4½ hours</td>
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<td>7-8½ hours</td>
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<tr>
<td>9 or more</td>
<td></td>
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<tr>
<td>27. Walk to do errands (such as to/from a store or to take children to school (count walk time only))?</td>
<td></td>
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<tr>
<td>□ YES How many TIMES a week?  ➔</td>
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<td></td>
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<tr>
<td>□ NO</td>
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<tr>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
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<tr>
<td>Less than 1 hour</td>
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<td>1-2½ hours</td>
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<td>3-4½ hours</td>
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<td>7-8½ hours</td>
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<tr>
<td>9 or more</td>
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<tr>
<td>28. Walk leisurely for exercise or pleasure?</td>
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<tr>
<td>□ YES How many TIMES a week?  ➔</td>
<td></td>
<td></td>
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<tr>
<td>□ NO</td>
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<tr>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
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<td>Less than 1 hour</td>
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<td>1-2½ hours</td>
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<td>3-4½ hours</td>
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<td>5-6½ hours</td>
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<td>7-8½ hours</td>
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<tr>
<td>9 or more</td>
<td></td>
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</tr>
<tr>
<td>29. Ride a bicycle or stationary cycle?</td>
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<tr>
<td>□ YES How many TIMES a week?  ➔</td>
<td></td>
<td></td>
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<tr>
<td>□ NO</td>
<td></td>
<td></td>
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<tr>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
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<td></td>
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<tr>
<td>Less than 1 hour</td>
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<tr>
<td>1-2½ hours</td>
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<td>3-4½ hours</td>
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<td>5-6½ hours</td>
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<td>7-8½ hours</td>
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<tr>
<td>9 or more</td>
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</tr>
<tr>
<td>Question</td>
<td>CHAMPS</td>
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<tr>
<td>-------------------------------------------------------------------------</td>
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<tr>
<td>In a typical week during the past 4 weeks, did you ...</td>
<td>CHAMPS</td>
<td></td>
</tr>
<tr>
<td>30. Do other aerobic machines such as rowing, or step machines (do not count treadmill or stationary cycle)?</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td>9 or 1-2½</td>
</tr>
<tr>
<td>□ YES  How many TIMES a week?_____</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td></td>
</tr>
<tr>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td></td>
</tr>
<tr>
<td>31. Do water exercises (do not count other swimming)?</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td>9 or 1-2½</td>
</tr>
<tr>
<td>□ YES  How many TIMES a week?_____</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td></td>
</tr>
<tr>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td></td>
</tr>
<tr>
<td>32. Swim moderately or fast?</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td>9 or 1-2½</td>
</tr>
<tr>
<td>□ YES  How many TIMES a week?_____</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td></td>
</tr>
<tr>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td></td>
</tr>
<tr>
<td>33. Swim gently?</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td>9 or 1-2½</td>
</tr>
<tr>
<td>□ YES  How many TIMES a week?_____</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td></td>
</tr>
<tr>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td></td>
</tr>
<tr>
<td>34. Do stretching or flexibility exercises (do not count yoga or Tai-chi)?</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td>9 or 1-2½</td>
</tr>
<tr>
<td>□ YES  How many TIMES a week?_____</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td></td>
</tr>
<tr>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td></td>
</tr>
<tr>
<td>35. Do yoga or Tai-chi?</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td>9 or 1-2½</td>
</tr>
<tr>
<td>□ YES  How many TIMES a week?_____</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
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<tr>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? Less than 1 hour</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>CHAMPS</td>
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<td>------------------------------------------------------------------------</td>
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<tr>
<td>In a typical week during the past 4 weeks, did you …</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Do aerobics or aerobic dancing?</td>
<td>□ YES  How many TIMES a week? _____ ➔</td>
<td></td>
</tr>
<tr>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
<td></td>
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<tr>
<td></td>
<td>Less than 1-2½ 3-4½ 5-6½ 7-8½ 9 or more</td>
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<td></td>
<td>1 hour hours hours hours hours</td>
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<tr>
<td>37. Do moderate to heavy strength training (such as hand-held weights</td>
<td>□ YES  How many TIMES a week? _____ ➔</td>
<td></td>
</tr>
<tr>
<td>of more than 5 lbs., weight machines, or push-ups)?</td>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
<td></td>
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<tr>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
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<td></td>
<td>Less than 1-2½ 3-4½ 5-6½ 7-8½ 9 or more</td>
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<td></td>
<td>1 hour hours hours hours hours</td>
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<tr>
<td>38. Do light strength training (such as hand-held weights of 5 lbs.</td>
<td>□ YES  How many TIMES a week? _____ ➔</td>
<td></td>
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<tr>
<td>or less or elastic bands)?</td>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
<td></td>
</tr>
<tr>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
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<td></td>
<td>Less than 1-2½ 3-4½ 5-6½ 7-8½ 9 or more</td>
<td></td>
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<tr>
<td></td>
<td>1 hour hours hours hours hours</td>
<td></td>
</tr>
<tr>
<td>39. Do general conditioning exercises, such as light calisthenics</td>
<td>□ YES  How many TIMES a week? _____ ➔</td>
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</tr>
<tr>
<td>or chair exercises (do not count strength training)?</td>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
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<tr>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
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<td>Less than 1-2½ 3-4½ 5-6½ 7-8½ 9 or more</td>
<td></td>
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<tr>
<td></td>
<td>1 hour hours hours hours hours</td>
<td></td>
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<tr>
<td>40. Play basketball, soccer, or racquetball (do not count time on</td>
<td>□ YES  How many TIMES a week? _____ ➔</td>
<td></td>
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<tr>
<td>sidelines)?</td>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
<td></td>
</tr>
<tr>
<td>□ NO</td>
<td>How many TOTAL hours a week did you usually do it? ➔</td>
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<td>Less than 1-2½ 3-4½ 5-6½ 7-8½ 9 or more</td>
<td></td>
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<td></td>
<td>1 hour hours hours hours hours</td>
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</tbody>
</table>
In a typical week during the past 4 weeks, did you ...

<table>
<thead>
<tr>
<th>41. Do other types of physical activity not previously mentioned (please specify)?</th>
<th>CHAMPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ YES How many TIMES a week? ____</td>
<td>How many TOTAL hours a week did you usually do it?</td>
</tr>
<tr>
<td>□ NO</td>
<td></td>
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</tbody>
</table>

Less than 1 hour | 1-2½ hours | 3-4½ hours | 5-6½ hours | 7-8½ hours | 9 or more hours |
Appendix W: Caregiver Assistance Scale

Care-giving Assistance Scale

We would like to know how much assistance you provide to the care recipient for each of the following activities, a rating of zero (0) indicates “no” assistance is provided, while a rating of six (6) indicates “a lot” is provided.

Please answer all questions to indicate your experience over the past month.

1. How much assistance do you provide in **transportation** (e.g., to and from hospital)?
   
<table>
<thead>
<tr>
<th>Rating</th>
</tr>
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<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>None</td>
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</tbody>
</table>

2. How much assistance do you provide in **giving medications/assisting with treatment**?
   
<table>
<thead>
<tr>
<th>Rating</th>
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<tbody>
<tr>
<td>0</td>
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<tr>
<td>None</td>
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</tbody>
</table>

3. How much assistance do you provide in **banking and financial management**?
   
<table>
<thead>
<tr>
<th>Rating</th>
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<tbody>
<tr>
<td>0</td>
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<td>None</td>
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</table>

4. How much assistance do you provide in **feeding**?
   
<table>
<thead>
<tr>
<th>Rating</th>
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<tbody>
<tr>
<td>0</td>
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<tr>
<td>None</td>
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</table>

5. How much assistance do you provide in **dressing**?
   
<table>
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<tr>
<th>Rating</th>
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<tbody>
<tr>
<td>0</td>
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<tr>
<td>None</td>
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</tbody>
</table>

6. How much assistance do you provide in **grooming** (e.g., combing hair, brushing teeth)?
   
<table>
<thead>
<tr>
<th>Rating</th>
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<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>None</td>
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</tbody>
</table>
7. How much assistance do you provide in toileting (e.g., going to bathroom)?

8. How much assistance do you provide in bathing?

9. How much assistance do you provide in ambulation (e.g., walking, moving around the home)?

10. How much assistance do you provide in transfers (e.g., bed to chair, chair to toilet)?

11. How much assistance do you provide in managing the emotional changes (e.g., crying spells, mood changes)?

12. How much assistance do you provide in communication (e.g., telephone, writing, reading)?
13. How much assistance do you provide in **co-ordinating, arranging, and managing services and resources** (scheduling appointments, arranging transportation, locating equipment and services, and finding outside help)?

0 1 2 3 4 5 6
None A Lot

14. How much assistance do you provide in **communicating with health professionals**?

0 1 2 3 4 5 6
None A Lot

15. How much assistance do you provide in **monitoring the health of the care recipient**? (e.g. weight, blood pressure)

0 1 2 3 4 5 6
None A Lot

16. How much assistance do you provide in **household responsibilities** (e.g. meal preparation, cleaning, yard care)?

0 1 2 3 4 5 6
None A Lot
17. How much assistance do you provide in managing behaviour problems of care recipient (e.g., irritability, irrational thoughts)?

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<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None</td>
<td>A Lot</td>
<td></td>
<td></td>
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</tbody>
</table>