

**“Look at me now. It is amazing.” Exploring the Stroke and Rehabilitation Experiences of  
Older Adults with Chronic Stroke Living in Thunder Bay**

by

Nicole P. Lee

Supervisor: Dr. Taryn Klarner-Read

Committee Members: Dr. Erin Pearson and Dr. Paolo Sanzo

In partial fulfillment of the requirements  
for the degree of Master of Science in Kinesiology

SCHOOL OF KINESIOLOGY

LAKEHEAD UNIVERSITY

THUNDER BAY, ONTARIO, CANADA

September 16, 2022

## Acknowledgements

I would like to express my greatest gratitude to my supervisor, Dr. Taryn Klarner-Read for her guidance, support, advice, and new opportunities she has given me over the past two years. I would not be the researcher I am without her guidance. I would also like to thank both of my committee members. Dr. Erin Pearson, thank you for teaching and guiding me through the new lens of qualitative research. I am excited to continue using all the guidance you have given me into my next stage as a researcher. Dr. Paolo Sanzo, thank you for your advice throughout the last two years and for your attention to detail throughout my manuscripts. It really has made me a better writer.

I would also like to thank the Thunder Bay Regional Health Sciences Center and St. Joseph's Care Group for their interest in this study. I am hopeful it showed a new perspective for stroke survivors here in Thunder Bay. In addition, thank you to the participants in this study. They were a big part of the success of this project. Finally, a big thank you to Couchiching First Nation as well for their continuous support in helping me achieve my academic dreams.

In addition, I would also like to thank my friends and family for their continuous support in helping me be successful throughout my graduate degree. I could not have done this without them. Lastly, I would like to thank the Kinesiology department, including faculty, staff, and my classmates for all the support and making these last two years so enjoyable.

## Abstract

**Introduction:** As stroke continues to be the leading cause of adult disability, understanding the rehabilitative needs of those affected is essential to ensure they are receiving proper care to reach their own sense of independence. This is particularly important for those living in cities such as Thunder Bay where there is a lack of resources and services. As seen in the literature, mainly quantitative measures have been used to gather information about stroke survivors' experiences. Through a qualitative lens, only surveys have been used; therefore, using semi-structured interviews allows participants to share their experiences by being able to expand on their thoughts. As there has been little research in Thunder Bay regarding stroke survivors' experiences, there is a need to speak with these individuals to fill this gap in the literature.

**Methodology:** A constructivist qualitative approach was used for this study. Participants were included if they were diagnosed by a physician with having a stroke, discharged from the hospital, had their most recent stroke more than six months ago, felt comfortable in engaging in an interview, and were able to give informed consent. Participants were excluded if they had a transient ischemic attack. A semi-structured interview was used to gather the participants' ideas and thoughts around their experiences throughout stroke recovery. The interview guide was developed into five different sections which included: introductory demographic questions, post-stroke life experiences, rehabilitation after stroke in Thunder Bay, barriers and facilitators to rehabilitation and exercise, and questions regarding the COVID-19 pandemic to see if it had impacted their rehabilitation and exercise. The interviews were transcribed verbatim and analyzed using thematic analysis.

**Findings:** Ten participants were interviewed including six males and four females whose ages ranged from 57-80 years of age. Two main categories emerged. The first was termed actual stroke experience, and had two overarching themes, along with four subthemes. These included: (1) *getting help is complex* (i.e., *checking with others first and not understanding situational urgency*); and (2) *the effects of stroke are multifaceted* (i.e., *losing physical abilities and undergoing mental hardships*). The second category termed the rehabilitation journey had four overarching themes, along with four subthemes including: (1) *losing rehabilitation services during the COVID-19 pandemic*; (2) *overcoming hardships, but not alone* (i.e., *positive encouragement to help make progress and needing support after secondary diagnosis*); (3) *“if you don't use it, you lose it”: rehabilitative success is based on one's actions* (i.e., *determination and open-mindedness about rehabilitation and forced independence can lead to next rehabilitation steps*), and; (4) *“look at me now”: the importance of taking pride in one's successes*.

**Conclusions:** From these findings, information regarding Northwestern Ontario and the three basic psychological needs were discussed. In addition, two recommendations were derived that will be presented to regional stakeholders which included needing to: 1) increase purposeful education to the general public about stroke, 2) help increase access to rehabilitation during the chronic stroke phase. This study allowed for participants voices to be recognized regarding the positive and negative experiences related to their care and share new perspectives pertaining to rehabilitation during the COVID-19 pandemic.

**Keywords:** Exercise, Experiences, Interviews, Rehabilitation, Stroke.

## List of Tables

Table 1. <i>Participant demographic data</i> .....	32
Table 2. <i>The rehabilitative journey of sample participants</i> .....	32
Table 3. <i>Quotes supporting theme 1: Getting help is complex</i> .....	44
Table 4. <i>Quotes supporting theme 2: The effects of stroke are multifaceted</i> .....	47
Table 5. <i>Quotes supporting theme 3: Losing rehabilitation services during the COVID-19 Pandemic.</i> ....	51
Table 6. <i>Quotes supporting theme 4: Overcoming hardships, but not alone</i> .....	54
Table 7. <i>Quotes supporting theme 5: “If you don’t use it, you lose it”: Rehabilitative success is based on one’s actions.</i> .....	57
Table 8. <i>Quotes supporting theme 6: “Look at me now”: The importance of taking pride in one’s successes.</i> .....	59

## List of Figures

Figure 1. *Themes and subthemes generated from category one: Actual stroke experience* ..... 41

Figure 2. *Themes and subthemes generated from category one: The rehabilitation journey* ... 49

## **List of Abbreviations**

**ACS-** Activity card sort

**CSEP-** Canadian society for exercise physiology

**COVID-19-** Coronavirus 2

**ESCROW-** Environment, social support, cluster of family members, resources, or work

**FAST Campaign-** Face, arm, speech, and time

**FIM-** Functional independence measure

**GDS-** Geriatric depression scale

**HRQOL-** Health related quality of life

**IADLq-** Instrumental activities of daily living questionnaire

**Li-Sat9-** Life-satisfaction questionnaire

**TIA-** Transient ischemic attack

## Table of Contents

Acknowledgements.....	ii
Abstract.....	iii
List of Tables .....	iv
List of Figures.....	v
List of Abbreviations .....	vi
Chapter One: Introduction .....	1
Overview.....	1
Review of the Literature .....	7
Background About Stroke.....	7
Lifelong Complications .....	8
Rehabilitation.....	8
Chronic Stroke .....	10
Rehabilitation Engagement After Stroke .....	11
Benefits of and Facilitators to Rehabilitation .....	11
Barriers to Rehabilitation Services .....	14
Best Practices in Ontario - Pathway Through Stroke Rehabilitation.....	16
Transition From Hospital.....	17
Permanent Nursing Home Care .....	17
Home Care .....	18
Long-Term Care Considerations for the Stroke Population .....	19
COVID-19 and Stroke Rehabilitation.....	20
Social Support Considerations During the Rehabilitative Process .....	22
Viewing One’s Health and Self After Stroke .....	23
Quality of Life.....	25
Approach to Understanding a Patient’s Personal Experiences .....	26
Chapter Two: Method.....	28
Study Design.....	28
Positionality of the Researcher .....	29
Participant Inclusion and Exclusion Criteria .....	29
Recruitment Process.....	30
<i>Semi-Structured Interview</i> .....	35
Data Analysis .....	36
Trustworthiness of the Data .....	37
Chapter Three: Findings .....	40
Participant Demographics.....	31

Overview of Themes and Subthemes .....	40
Actual Stroke Experience .....	40
<i>Getting Help is Complex</i> .....	41
<i>The Effects of Stroke are Multifaceted</i> .....	44
The Rehabilitation Journey .....	48
<i>Losing Rehabilitation Services During The COVID-19 Pandemic</i> .....	49
<i>Overcoming Hardships, But Not Alone</i> .....	51
“If you don’t use it, you lose it”: Rehabilitative Success is Based on One’s Actions .....	55
“Look at me now”: Taking Pride in One’s Successes .....	58
Chapter Four: Discussion.....	60
Actual Stroke Experiences.....	60
<i>Physical and Mental Effects After Stroke</i> .....	60
The Rehabilitation Journey .....	63
<i>Stroke Rehabilitation in Northwestern Ontario</i> .....	63
<i>Supporting the Self-Determination Theory’s Basic Psychological Needs After Stroke</i> .....	66
Future Implications for Stakeholder Groups.....	70
<i>Purposeful Education About Stroke Signs and Symptoms Needed for General Public</i> .....	70
Study Strengths .....	75
Study Limitations.....	76
Chapter Five: Conclusion .....	78
References.....	79



## Chapter One: Introduction

### Overview

At least every 30 minutes, one new person has a stroke in Ontario, and this rate will continue to increase with our aging population (Andres et al., 2017). As a large portion of the population is affected by stroke, increased rehabilitation access and services are essential. When a stroke occurs, blood stops flowing to the brain through either a rupture or complete blockage where no oxygen or blood can reach the brain (Frizzell, 2005). Although this is the general process of a stroke, there are also three specific types of strokes. These include an ischemic stroke, a hemorrhagic stroke, and a transient ischemic attack (Frizzell, 2005). There are also many lifelong complications after a stroke that are dependent on which part of the brain has been damaged, along with the amount of damage done (Sandeep et al., 2010). Brain damage from a stroke can affect the individual in many ways including changes to their physique, emotions, personality, thinking, perception, communication, and everyday living arrangements (Northcott et al., 2015). After six months post-stroke, individuals then reach a steady state of recovery called chronic stroke (Sun et al., 2015). This is where improvements are still possible, although progress may seem slower as they have reached a steady state of recovery (Sun et al., 2015). As rehabilitation is still a vital part of one's recovery during the chronic stage, the focus then shifts to recovering independence and regaining functional abilities at home (Gresham et al., 2004). One way to reach these goals is through exercise which is a common type of rehabilitation known for its positive effects seen to the body, but also the improvements seen in relation to the psychosocial effects from a stroke (Eng et al., 2015).

For someone who has had a stroke, both exercise and general physical activity are important to the rehabilitative process (Eng et al., 2015). Physical activity differs from exercise

as it is defined as movement implemented by the skeletal muscles that requires energy, whereas exercise is planned with structured movements (Fahey et al., 2016). After a stroke, physical inactivity is very common due to the sudden life-changing ramifications associated with having a stroke (Kunkel et al., 2014). As a result, physical inactivity can inhibit individuals from reaching their long-term goals regarding improvements to their impairments, functional limitations, and general well-being (Saunders et al., 2014). Due to the effects that sedentariness can have on an individual after a stroke, physical activity is important to maintain throughout the chronic stroke stage once an individual has left the hospital or long-term care facility (Kunkel et al., 2014). Remaining inactive can pose many risks for an individual's health including diseases like obesity, and negative effects on psychological health (Gaetano, 2016). Therefore, it is important for individuals who have had a stroke to implement structured activity such as exercise to aid in the rehabilitation process (Gateano et al., 2016).

To increase the amount of exercise for those who have had a stroke, it is important to understand the facilitators and barriers they may face. Michael et al. (2015) implemented exercise sessions for stroke survivors to examine the efficiency of physical activity during the rehabilitative process. Some of the reported benefits included improvements in gait, balance, ambulatory performance, health related quality of life, and an overall increase in life satisfaction post-stroke (Michael et al., 2015). A meta-analysis conducted by Chen et al. (2011) involved searching for randomized controlled trails regarding exercise on health-related quality of life (HRQOL). Results showed that exercise had a medium effect on HRQOL, meaning that exercise does improve HRQOL (Chen et al. 2011). As both of these studies showed the importance that exercise has on stroke survivors' health and well-being, it is evident that exercise does need to be implemented within this population's rehabilitation.

Despite the numerous benefits exercise can provide to stroke survivors, there have also been studies concluding that these individuals are not made aware of the benefits exercise can give them (Nicholson et al., 2017). It is important to ensure that all information regarding rehabilitation and exercise is understood by patients as this may be something they want to partake in. In particular, stroke survivors also face many barriers to initiating rehabilitation and exercise such as previous trauma from the stroke, lack of motivation and, in particular, a lack of available services (Donio et al., 2020; Nicholson et al., 2017). Geographical disparities can exist whereby those in more remote locations or smaller townships have less access to rehabilitative services and programs. For example, a 2017 study found that people in Southern Ontario experienced half as many cardiovascular events from a sample of five million participants (Shurrab et al., 2017). It was reported that those in this region had more access to healthcare systems, more medical visits and check ins, and a lower rate of re-admission after a stroke compared to Northwestern Ontario cities such as Thunder Bay, resulting in worse outcomes for patients in the North (Shurrab et al., 2017). Although there are differences in availability and access to rehabilitation services between Northwestern and Southern Ontario, there is a lack of research regarding one's experiences with access and use of services including barriers and facilitators faced among stroke survivors, specifically in Thunder Bay.

Once an individual is discharged from the hospital, the rehabilitative process begins. This occurs once the acute effects from the stroke have been evaluated and the person is deemed safe to partake in rehabilitation and it is appropriate to leave (Andres et al., 2017). The individual can then be sent to a rehabilitation unit, a long-term care home, or back to their own home with family, depending on what is needed or required. Although it may not be right away, most individuals are able to return home after being away for rehabilitation or inpatient care (Andres

et al., 2017). When a decision is made, it is important to ensure the family is also a part of this conversation as they often become primary caregivers (Gresham et al., 2004). Once individuals are back living in their home, understanding their long-term needs is also essential from the patient, family, and healthcare team's point of views. In 2017, a study was conducted which found that many of the needs for stroke recovery were not being met in Canada by the hospitals and healthcare providers (Andres et al., 2017). For example, rural Northwestern Ontario communities have a hard time addressing long-term care needs for their residents as they lack hospitals, healthcare providers, and roads; therefore, these individuals are often required to travel outside of their community (Winn et al., 2014).

Due to the recent Coronavirus 2 (COVID-19) pandemic, the pathway through stroke rehabilitation has shifted. It has made it much more difficult for individuals to access rehabilitation services as communities have lost most or all of their services, resources, and sense of community due to related public health restrictions (Kapral et al., 2020). As time passed throughout the pandemic, at-home rehabilitation has become more important in response to the ongoing related restrictions in place through virtual methods of delivery (Torriani-Pasin et al., 2021). This has been particularly seen for those who had a stroke (Torriani-Pasin et al., 2021). Given the novelty and recent emergence of virtual rehabilitation, exploring experiences related to virtual and hybrid delivery models is both timely and warranted.

In addition to the drastic physical changes that take place for someone who has had a stroke, their personal view of their own health also changes (Kitzmuller et al., 2013). By being able to understand these changes, family members and healthcare teams can work towards empathizing with these individuals and helping them feel comfortable with the new living situation they will be faced with (Taule & Raheim, 2013). One significant change these

individuals face is their own perception of living. This can include thinking their body is fragile, fatigued, unfamiliar, or unreliable, while often objectifying themselves (Kitzmuller et al., 2013). Quality of life is another significant change; post-stroke depression is very common, along with negative thoughts in relation to their body, mind, and ability which have been seen to decrease overall quality of life (Taule et al., 2015). Despite all the negative ramifications one may face after a stroke, it is important to keep these individuals in high spirits to allow for the rehabilitation process to be easier for the patient, family, and healthcare providers (Sugavanam et al., 2012). This can be done by reminding them of their goals or routines and how these will help the process (Kitzmuller et al., 2013). By being able to keep individuals accountable and in a positive mindset, reminding them that they are working toward a goal can be very beneficial to their overall perception of themselves and quality of life (Sugavanam et al., 2012)).

Within any population, specifically those that have undergone a lifechanging experience such as a stroke, understanding their personal experience is important to gain a broader perspective on a concept (Rego, 2021). Personal experiences can be described as knowledge that is obtained through the individual directly, rather than from someone else (Rego, 2021). In order to understand someone's experience, directly speaking to the person and allowing them to explain their own experiences specifically with a chronic disease such as stroke, is essential to gain insight into the condition.

As stroke continues to be the leading cause of adult disability in Canada, understanding the rehabilitative needs of these individuals is essential to ensure they are receiving proper care to reach their own sense of independence (Andres et al., 2017). This is particularly important for those living in cities such as Thunder Bay where there is a lack of resources and services (Shurrab et al., 2017). As seen in the literature, mainly quantitative measures have been used to

gather information about stroke survivors' experiences (Brajkovic et al., 2009; Chen et al., 2011; Michael et al., 2015; Nicholson et al., 2017; Rimmer et al., 2008). Through a mixed methods lens, surveys have been used, however, to allow participants to rank barriers on a scale from one to ten out loud to researchers, therefore favouring the quantitative methodology (Nicholson et al., 2013; Taule et al., 2015). Therefore, using a qualitative research approach will allow for participants to share their experiences by being able to expand on their thoughts and experiences. As there is limited research in Thunder Bay regarding stroke survivors' experiences, there is a need to speak with these individuals to further fill this gap in the literature. In addition, due to the recent COVID-19 pandemic, there is also limited research regarding the related effects on the rehabilitation field, specifically stroke rehabilitation. Thus, the purpose of this qualitative constructivist study was to explore the personal stroke and rehabilitation experiences of older adults with chronic stroke living in Thunder Bay using semi-structured interviews. It is hoped that the outcomes of this research can be used to optimize the recovery experiences for future survivors from a wellness perspective.

## Review of the Literature

### Background About Stroke

To date, stroke continues to be the leading cause of disability in Canada and is the third leading cause of death (Andres et al., 2017). Within Canada, about 426,000 people are living with the effects of stroke; Ontario contributes to this number at least every 30 minutes when a new stroke occurs (Andres et al., 2017). A stroke can be described as when blood stops flowing to the brain and further damages one's brain cells (Frizzell, 2005). This happens in two ways whereby either a rupture or blockage prevents oxygen and blood from reaching the brain, resulting in a stroke. There are three different types of strokes that an individual may have. These include an ischemic stroke, a hemorrhagic stroke, and a transient ischemic attack (TIA; Frizzell, 2005).

An ischemic stroke is caused by a blood vessel becoming blocked or clotted in the brain. This occurs when plaque begins to build up on the inside wall of an artery, becomes dislodged, and gets stuck in the small blood vessels of the neck and head (Frizzell, 2005). A hemorrhagic stroke is caused when an artery in the brain ruptures interrupting the flow of blood, resulting in damage to the brain. This may be due to high blood pressure which weakens the arteries over time (Frizzell, 2005). A TIA, also known as a mini-stroke or warning stroke, occurs when there is a small clot that briefly blocks an artery. The symptoms will usually last for under an hour, meaning the side effects are not long-term; however, this type of stroke is a warning sign that a more serious stroke may occur (Frizzell, 2005). There are many risk factors that may predispose an individual to having a stroke. These can include, but are not limited to, an unhealthy diet, physical inactivity, unhealthy weight, smoking, stress, excessive alcohol consumption, and drug abuse (Frizzell, 2005). As the different types of strokes can all cause life-long damage,

immediate medical attention is required to try and prevent any further complications (Murali & Hemachandra, 2016).

### **Lifelong Complications**

After a stroke occurs, regardless of the cause and even if immediate attention is taken, there is likely to be some variation of minor or major lifelong complications (Murali & Hemachandra, 2016). The effects depend on which part of the brain has been damaged, but also the amount of damage to that area (Sandeep et al., 2010). Stroke can also influence motor, sensory, and cognitive functioning depending on which structure and area of the brain is affected (Bolognini et al., 2016). The effects of the stroke are also present on the opposite side of the body the stroke occurs on (Bethoux et al., 1999). This is because one side of the brain controls the opposite side of the body, meaning when a stroke occurs on one side of the body, the neurological complications will be seen on the contralateral side (Sandeep et al., 2010). In addition to the specific long-term immediate effects from a stroke, there are also physical, emotional, and personality changes, thinking, and perception changes, communication changes, and everyday changes such as living arrangements, ability to work, and level of independence (Northcott et al., 2015). Although the lifelong implications for a stroke vary by individual and the type of stroke experienced, the implications affect individuals similarly because they share comparable physical, mental, and emotional hardships (Northcott et al., 2015).

### **Rehabilitation**

Stroke rehabilitation is a complex set of processes where multiple professional disciplines are involved with the goal of improving the quality of life for people who have had a stroke (Young, 2007). As the ultimate goal for any individual who has had a stroke is to find a new sense of independence, rehabilitation is key to ensure this process can occur (Gresham et al.,



2004). Since this process is essential to the individual's future, it is a process that needs to start right away (Sandeep et al., 2010). Essentially, the purpose of the rehabilitative process is to regain function, prevent other complications, relearn skills, learn new ways to perform tasks, and limit the reoccurrence of a future stroke (Gresham et al., 2004). Although the process itself may look different on a case-by-case basis, rehabilitation will help guide the individual to meet their long-term goal of independence and to regain functional abilities. This can initially occur via treatment at inpatient rehabilitation hospitals and units in acute care hospitals, in addition to nursing homes, outpatient facilities, or at home (Gresham et al., 2004). Rehabilitation should be tailored to the individual's needs, short- and long-term goals, and their current living situation (Sun et al., 2015).

One specific type of rehabilitation that is common within stroke rehabilitation is the use of exercise (Billinger et al., 2014). Exercise can be defined as planned, structured, repetitive movements that are intended to improve or maintain one's fitness levels (Fahey et al., 2016). As this type of rehabilitation may not be for every individual right away, it is important for the patient to work with their healthcare team to decide when exercise is a good addition to the continuum of care (Sandeep et al., 2010). Due to the complexity of stroke complications, it is essential to have the clearance to start exercising and ideally have a member of the healthcare team or family member available to support the individual throughout all phases of their exercise and rehabilitation journey (Koehn et al., 2021).

Exercise for this population can take many different forms including independent exercise, community groups, and home-based programming via aerobic conditioning, strength training, stretching, and balance activities (Saunders et al., 2014). For stroke survivors, the recommended frequency of training is three to seven days a week, with a duration of 20-60

minutes, depending on the patient's fitness level (Gordon et al., 2004). Exercise can help increase important rehabilitation outcomes, such as improving functional capacity, the ability to perform activities of daily living, and reducing the risk of subsequent cardiovascular events (Billinger et al., 2014). Exercise is also able to combat the negative psychosocial effects of a stroke which can be very difficult for most (Eng et al., 2015). When someone participates in exercise, there is a release of the brain's "feel-good" neurotransmitters called endorphins (Chen et al., 2011). Endorphins can decrease the effects of stress on the body, improve general mental health and mood, and enhance memory and cognition which can be particularly important for someone who has had a stroke (Chen et al., 2011). As there are many benefits that exercise gives to individuals, both physically and mentally, it is essential for healthcare providers to encourage the patients to engage in exercise, in addition to further teach the patients about the importance of exercise (Lovell et al., 2010).

### **Chronic Stroke**

As time passes from the initial stroke, some acute (short term) outcomes may improve because of rehabilitation; however, if stroke-effects are significant, the individual may need to focus on their lifelong rehabilitation needs (Sun et al., 2015). Chronic stroke is defined as the period of recovery that lasts at least six months after the initial stroke (Sun et al., 2015). This chronic stage is important because it allows patients to be familiar with their current situation as they have reached that steady state of recovery (Sun et al., 2015). This allows the patient, along with their healthcare team, to work on goals that are important to their everyday life and long-term perseverance; living with the effects from a stroke can be difficult. Rehabilitation is still very important in this phase to maintain progress from the acute phase (before six months post-stroke), but also to maintain and facilitate other improvements over time (Gresham et al., 2004).

Although changes and advancements may not be seen as often as in the chronic stage, these improvements become more meaningful as those who have suffered a stroke begin to change their way of life (Sun et al., 2015).

### **Rehabilitation Engagement After Stroke**

Just as exercise is a crucial part of one's post-stroke rehabilitation process, it is important to understand the influence of physical activity as well. Physical activity can be defined as a movement implemented by the skeletal muscles that requires energy (Fahey et al., 2016). This differs from exercise, as physical activity is not planned or structured, but instead can include a variety of movements such as walking, gardening, home/yard work, and cleaning (Fahey et al., 2016). Physical activity is essential as it can improve one's health and wellness because of the wide range of benefits it confers, similar to exercise (Fahey et al., 2016). After a stroke, exercise and physical fitness are impaired which can continue to worsen because of the sedentary lifestyle that can occur (Saunders et al., 2014). For an individual who has had a stroke, ensuring adherence to physical activity and exercise after the initial rehabilitation process is continued is important to help maintain their goals (Rimmer et al., 2008). This can also help individuals improve their activities of daily living (tasks that are undertaken every day to maintain level of care including feeding, dressing, and mobilising; Legg et al., 2007) which is most often affected after stroke (Legg et al., 2007). As this can be a difficult process for the patient, it is important to understand what benefits and facilitators the individual faces and the barriers they may experience in relation to their rehabilitation engagement.

### **Benefits of and Facilitators to Rehabilitation**

Exercise, although studied widely within the general population, has also been studied specifically within the stroke population (Chen et al., 2011; Michael et al., 2015; Nicholson et al.,

2017). An experimental design was used to implement exercise sessions in seven stroke survivors three times a week for six months and examined the efficiency of adaptive physical activity (Michael et al., 2015). Results from the Berg Balance Scale, Dynamic Gait Index, Six-Minute Walk, and cardiovascular fitness tests (VO<sub>2</sub> peak) showed increases from the original baseline scores (Michael et al., 2015). The researchers concluded that structured exercise sessions do produce improvements for balance, gait, fitness, and ambulatory performance among stroke survivors (Michael et al., 2015). This study gave insight and understanding to healthcare providers, individuals who had a stroke, and their families as to why exercise was important to post-stroke recovery. Michael et al. (2015) also showcased how structured activity did provide benefits for those after having a stroke.

As physical and psychological factors change significantly after stroke, it is rewarding for these individuals to see that improvements are possible through exercise (Gaetano, 2016). In terms of psychosocial health benefits linked to exercise after stroke, a meta-analysis was used to report on randomized controlled trials examining the effects of exercise on health-related quality of life (HRQOL; Chen et al., 2011). Studies that were included needed to meet the following criteria: 1) recruited only stroke survivors; 2) no other disability groups were included; 3) exercise was the primary intervention; 4) HRQOL was a targeted outcome; and 5) only used randomized controlled trials (Chen et al., 2011). The results showed that interventions with aerobic and strength training showed greater changes in HRQOL, specifically among chronic stroke survivors. Therefore, the paper revealed that exercise does improve HRQOL; however, it was recommended to find strategies to sustain the effects after completing exercise interventions (Chen et al., 2011). It is possible that exploring participant experiences qualitatively may provide insights into achieving this goal, as qualitative studies were excluded from this study.

Exercise has also been shown to increase overall life satisfaction among stroke survivors in comparison to those who were inactive post-stroke (Hartman-Maeir et al., 2009). A total of 56 stroke patients who completed in-patient rehabilitation programming were evaluated one year post-stroke in their own home by using the Functional Independence Measure (FIM), Instrumental Activities of Daily Living Questionnaire (IADLq), Activity Card Sort (ACS), a work questionnaire, Life-Satisfaction Questionnaire (Li-Sat9), and the Geriatric Depression Scale (GDS). The results showed significant correlations between overall life satisfaction scores and the overall scores from FIM, IADLq, and ACS (Hartman-Maeir et al., 2009). It was also concluded that activity levels were a significant predictor of life satisfaction. Results also revealed a need for rehabilitation services to focus on IADL and leisure activities. Although Hartman-Maeir et al. (2009) showed the need for rehabilitation services through a quantitative design, it was recommended to interact with the participants through a qualitative methodology to understand more deeply, what they think would be beneficial to increase their overall life satisfaction post-stroke.

As the research in this population continues to grow, it is evident that individuals living with the effects from a stroke and their healthcare team need to be mindful of the patients' reasons and values when considering exercise as a part of their rehabilitation (Hall et al., 2020). For example, Nicholson et al. (2017) completed structured interviews with 47 participants about their perceived barriers and motivators regarding physical activity after stroke. These interviews were designed by using a predetermined list of possible motivators and asking the participants to rank them. Results showed that "exercise is good for your health" was the most commonly reported motivator (Nicholson, 2017, p. 232). This was followed by "to become fitter," "to feel in good shape mentally," and "to feel in good shape physically" (Nicholson et al., 2017, p. 232).

This study showed the importance of speaking with individuals who had a stroke as it gave them the autonomy to highlight their own needs. However, as this study did not allow for much discussion from participants due to the structured format, it showed the need to understand why stroke survivors experience different barriers and motivators to physical activity. The authors recommended that it would be beneficial to hear from the participants to understand further if these truly are the reasons these participants exercised or if there were other motivators they would have included (Nicholson et al., 2017).

### **Barriers to Rehabilitation Services**

Despite the countless benefits associated with rehabilitation, barriers are very common within the stroke population for many reasons including the previous stress and trauma they experienced (Pacheco et al., 2019). In general, stroke survivors do not meet the exercise guidelines for their age according to the *Canadian Society for Exercise Physiology* (CSEP) due to the sedentary behaviour that often follows a stroke (Billinger et al., 2014). Through this sedentary lifestyle and the effects after a stroke, individuals may face barriers to performing their activities of daily living which were once simple to them (Mercier et al., 2001). These effects can impact motor, cognitive, and perceptual ability of their functional autonomy which may present other barriers such as a lower perception towards their perceived ability to complete tasks (Mercier et al., 2001). Some other barriers that this population faces include lack of motivation and environmental factors such as transportation, health concerns, and stroke impairments (Nicholson et al., 2012). In regards to exercise specific rehabilitation, Nicholson et al. (2017) had participants rank a list of predetermined barriers to physical activity after stroke. It was concluded that “poor health” and “feeling too tired” were the most commonly reported (Nicholson et al., 2017, p. 232). Again, although this study gave insight into which barriers

stroke survivors perceived as having the greatest influence, researchers recommended that further discussion with the participants would be of interest to understand why stroke survivors reported these barriers most often (Nicholson et al., 2017).

Another important barrier to accessing physical activity is environmental factors. Nicholson et al. (2012) completed a systematic review of perceived barriers to physical activity after stroke. This paper included five qualitative and one quantitative article; the authors concluded that environmental factors such as transport, cost, and access to services were among the most reported barriers (Nicholson et al., 2012). Similarly, Rimmer et al. (2008) analyzed the personal and environmental barriers of those who had a stroke more than six months ago in an urban area through The Barriers to Physical Activity and Disability Survey (Rimmer et al., 2000). It was concluded that 96% of participants were interested in starting an exercise program; however, environmental factors were stopping the participants from doing so (Rimmer et al., 2008). This included 61% who acknowledged cost as a barrier, 57% who were unaware of an appropriate facility in their neighbourhood, and 57% who noted that they did not have a method of transportation to a fitness facility (Rimmer et al., 2008). An important area of future research for investigation noted by the researchers was to work with this population in helping remove these environmental barriers in order to better adhere to exercise. As this study gave insight into specific personal and environmental barriers in an urban area, it may be beneficial to further explore these barriers from a participant's point of view among those living in more remote areas. For example, discussing with participants their experiences to further understand why these barriers may be present could provide insight into how to mitigate these barriers.

One specific barrier that is difficult to address is one's location of living (Nicholson et al., 2013). Although it is complex, working to mitigate the barriers associated with one's location is

important. Dr. Mubeen Rafay, Clinical Scientist, acknowledged that health-related services and supports are more abundant, and readily accessible in larger cities, compared to Northern areas (Andres et al., 2017). This may include services such as specialized health professionals, or general access to hospitals and facilities which can be a major barrier to individuals living in areas outside of main cities (Andres et al., 2017). For example, Shurrab et al. (2017) concluded that in comparison to Northern Ontario cities such as Thunder Bay, Southern Ontario had greater access to healthcare systems, more visits, and more check ins. Specifically in Northwestern Ontario, readmission rates were higher for those who had a cardiovascular event, such heart attack or stroke, compared to those living in Southern Ontario (Donio et al., 2020). Due to the disparities between the North and South, Northwestern Ontario residents are more susceptible to worse outcomes because of a lack of resources and services (Shurrab et al., 2017). As the readmission rates are evident in Northwestern Ontario, it can be argued that there may be limited opportunities and accessibility challenges due to the specific regional barriers. Therefore, further exploration into the unique experiences those in the North face is necessary to understand this population's challenges.

### **Best Practices in Ontario - Pathway Through Stroke Rehabilitation**

Looking ahead at what the future may entail for someone who has had a stroke can be very difficult for a variety of reasons. To begin, it is difficult to truly understand what rehabilitative pathway the individual may take as it can include many options (Eng et al., 2015). Whichever rehabilitation setting is deemed appropriate for the individual, there are then a variety of factors that dictate this new experience for them (Winn et al., 2014). It is therefore important to understand the overall care and well-being for both the individual and their family, as the pathway they are taking is much different than anything they were used to before the stroke (Eng



et al., 2015). As a result, it is important to understand the stages from being discharged from the hospital to their home, along with their long-term rehabilitative care needs, and how the COVID-19 pandemic may have impacted this process.

### **Transition From Hospital**

Before the healthcare team, family, and patient decide on what the long-term rehabilitative process may look like, they must face the reality of what is to come in the short term (Taule & Raheim, 2013). This includes time in the hospital, beginning rehabilitation, and many meetings with the rehabilitation team and other specialists (Anderson et al., 2000). Once the patient's effects from the stroke have been evaluated and the conversation about rehabilitation has begun, the patient's next step is to be discharged from the hospital (Taule et al., 2015). This can be a stressful time for both the patient and family, as there are many factors to keep in mind such as where the patient will be living. For this population, it is important to understand that the recovery process affects every individual and their family members differently based on the scenario at hand (Lawrence et al., 2010).

### **Permanent Nursing Home Care**

Depending on the severity of the stroke, a patient may be required to live in a nursing home due to the extra support provided there (Strum et al., 2002). Brajkovic et al. (2009) conducted a study with 60 elderly men and women, where 30 participants lived in their own home, and 30 lived in a nursing home. Both groups filled out a survey package including the World Health Organization Quality of Life Questionnaire, Self-Assessed Quality of Life Questionnaire, and a demographic questionnaire regarding subjective quality of life. The survey results revealed that the individuals living in the nursing home had significantly higher quality of life scores and higher perceived health scores (Brajkovic et al., 2009). It was concluded that this

was because the nursing home provided 24-hour health services, structured social time, encouraged social interaction, and offered sufficient exercise, while catering to the patient's needs. As a result, it can be argued that the lack of structure at home in comparison to a nursing home may propose challenges to those who live at home after stroke. Due to this, exploring the challenges those at home face after stroke is needed to help mitigate any hardships that are discovered (Brajkovic et al., 2009).

### **Home Care**

If the healthcare team, family members, and individual decide home will be the most appropriate living environment, arranging the transition will be the next step following discharge from the hospital (Taule & Raheim, 2013). Many people can return home eventually, whether it is after completing their rehabilitation or inpatient hospital care (Andres et al., 2017). It was reported that 58% of stroke patients returned home after being hospitalized and 68% returned home after receiving inpatient rehabilitative care (Andres et al., 2017). In Northwestern Ontario, inpatient care can be difficult for individuals living hours from key stroke services as they are far away from their family (Kapral et al., 2020). Kapral et al. (2020) used the Ontario Road Network database associated with the Ontario Acute Stroke Care Resource Inventory (Hall et al., 2016) to estimate the number of people in rural communities who were 30, 60, or 240 minutes of travel time away from stroke services. Individuals in rural communities were defined as any individual living in a community with a population size under 10,000 (Kapral et al., 2020). It was concluded that of the 1,496,262 people included, 68% lived within 60 minutes of a stroke unit, 74% within 60 minutes of a stroke prevention clinic, and 66% within 60 minutes of an inpatient rehabilitation centre (Kapral et al., 2020). It was also concluded that individuals who lived more than an hour away decided not to undergo inpatient rehabilitative care and instead, live at home.

This study showed evidence of good overall geographical access to most stroke services; however highlighted that sometimes these services are not being used (Kapral et al., 2020). Therefore, it may be beneficial to further explore the patients' thoughts and perceptions as to why they are or are not utilizing the care that is within 60 minutes of their home.

### **Long-Term Care Considerations for the Stroke Population**

For individuals who have had a stroke, it is evident that there are many specific rehabilitative care needs. The Heart and Stroke Foundation 2017 report found that overall, many of the rehabilitation care needs for stroke recovery are not being met by healthcare teams (Andres et al., 2017). For example, only about 16% of stroke patients who leave inpatient acute hospital care get into inpatient rehabilitation right away (Andres et al., 2017). This was found through consulting 600 Canadians who had a stroke or heart disease, along with their family or caregivers. It was also concluded that the individual's needs vary according to factors such as location, severity, age, and availability/access to local programming (Andres et al., 2017). Psychosocial needs were also found to be important as these individuals live with the effects for the rest of their lives (Andres et al., 2017). This cohort also commented on the difficulty of transitioning from acute care back to the community as they had gone from having a high level of personal care to experiencing feelings of isolation (Andres et al., 2017). As it had been established that these rehabilitative care needs were important to this specific cohort, ensuring that an effort is being made to meet these needs is critical for the longevity of care of this population.

In Northwestern Ontario, long-term care considerations for those who have had a stroke are important, as this population faces different barriers based on their location. As the cities in Northwestern Ontario are isolated, such as Thunder Bay, the lack of resources such as hospitals

and healthcare providers make it more difficult for these individuals to receive long-term care after their stroke (Winn et al., 2014). In the larger cities throughout Northwestern Ontario (e.g., Thunder Bay), hospitals are responsible for providing care to the smaller towns and communities. For this reason, Northern Ontario hospitals are susceptible to becoming overwhelmed, in comparison to the hospitals in Southern Ontario (Kapral et al., 2020). As this is possible, it can be argued that the differential access to recourses needs to be acknowledged when creating rehabilitation programs for the stroke population in cities like Thunder Bay.

### **COVID-19 and Stroke Rehabilitation**

Throughout the COVID-19 pandemic, Canadian communities lost most or all access to services, resources, and sense of community due to the public health restrictions (Smith et al., 2020). As such, stroke admissions and care rehabilitation have been difficult on the patients, families, and even the healthcare teams (Smith et al., 2020). As the situation escalated very quickly, it was difficult for all to truly understand what is best for any individual, especially those living with a condition such as stroke. Due to the pandemic, there has been a drop in stroke-related admissions because patients are not willing to go to the hospital due to a fear of contracting the virus (Wiley, 2020). Stroke awareness has also decreased (Hickey et al., 2018). For example, it has become harder to tell when people are having a stroke due to wearing masks (e.g., facial drooping) and when slurred speech is present (e.g., reduced verbal communication; Wiley et al., 2020). In addition to low admissions and awareness, access to stroke rehabilitation has also significantly decreased during this time (Smith et al., 2020).

Since the pandemic began, individuals have been discharged directly to the community from acute care after a stroke which has limited their access to stroke rehabilitation (Torriani-Pasin et al., 2021). Those with inpatient rehabilitation have also had a reduced stay due to

COVID-19 which has made the process harder on these individuals (Smith et al., 2020). In exchange for in-person assessments and appointments, telerehabilitation has been used more often during the pandemic (Smith et al., 2020). Telerehabilitation is where the delivery of rehabilitation services takes place over the phone or internet, and it allows both the healthcare provider and patient to provide and receive services remotely (Smith et al., 2020). Throughout the COVID-19 pandemic, telerehabilitation has been an effective and well-accepted method of providing outpatient and community rehabilitation services to those who had a stroke (Smith et al., 2020). Telerehabilitation allowed for patient's to still receive care if required by assessing their situation through the phone or Wi-Fi compatible device. The healthcare provider then decided what steps would be next for the individual, while keeping the individual safe at home from the virus.

Prior to the COVID-19 pandemic, at home rehabilitation was becoming increasingly popular due to healthcare teams wanting to move away from traditional programs as these did not work for everyone (Smith et al., 2020). Chaiyawat et al. (2012) conducted a study to examine the effectiveness of a six-month home rehabilitation program for those who had an ischemic stroke. A randomized controlled trial design was used in which 60 patients were assigned to receive either a home rehabilitation program or usual care. The home rehabilitation program included a physical therapist once a month, along with individual counselling. The usual care group was given instructions for home rehabilitation prior to discharge and had no follow-up home visits (Chaiyawat et al., 2012). The Barthel Index, the modified Rankin Scale, and utility index scales measured function, disability, and quality of life of both groups (Chaiyawat et al., 2012). The results concluded that early home rehabilitation in the first six months after an ischemic stroke led to rapid improvements in function, reducing disability, and increased quality

of life compared to usual care (Chaiyawat et al., 2012). As this study used quantitative measures, it would be beneficial to use a qualitative approach, such as interviews, to allow the participants to speak about their experiences and gather new data. Due to the novelty and recent emergence of this type of rehabilitation, it is both timely and warranted to understand the personal experiences of those who have undergone this type of rehabilitation.

### **Social Support Considerations During the Rehabilitative Process**

Regardless of the pathway an individual undergoes for rehabilitation, social support is one factor that is necessary to the process (Cameron, 2013). It is important for the patient to have a source of support, as the effects from a stroke are life changing (Eng et al., 2015). Although having a stroke is a catastrophic event for any individual, the effects are also very difficult on the family. Including the family is a major part of the rehabilitation process in order to provide support and adjust to the new lifestyle with their family member, especially when deciding to live at home (Gresham et al., 2004). For many, changes need to be made at home to accommodate a new way of living (Eng et al., 2015). This can include physical changes such as bathroom modifications so the individual can live comfortably, schedule planning to ensure rehabilitation meetings and appointments are being met, and addressing mental health changes as this is a big change for everyone within the household (Eng et al., 2015).

Educating the family about the condition and giving resources for the caregivers is one way to help make the process easier for the family (Cameron, 2013). Evans et al. (1991) prospectively investigated the effects that stroke and social support have on the delivery and success of home care. One hundred and thirty-five individuals who had a stroke and their primary support person were evaluated after initial hospitalization and one-year post-stroke. There were five measures used to analyze different constructs in relation to both the patient and

caregiver which included: the Center for Epidemiologic Studies – Depression Scale, Cognitive Capacity Screening Exam, ESCROW (environment, social support, cluster of family members, resources, work, or school status) Profile, Stroke Care Information Test, and Family Assessment Device (Evans et al., 1991). It was concluded that households with satisfactory homecare situations at one-year post-stroke had a caregiver who was: 1) more likely to be depressed, 2) less likely to be married to the patient, 3) below average in knowledge about stroke care, and 4) reporting more family dysfunction (Evans et al., 1991). The results from this study showed how caregiver-related problems had a direct effect on the rehabilitation outcomes of the patient (Evans et al., 1991). Therefore, it is of interest to also gain information about the patient's social support network as it may dictate their experience throughout the rehabilitative process. Whether it is through direct contact with the caregiver, or through the patient's point of view, understanding what their life is like at home is important.

### **Viewing One's Health and Self After Stroke**

Due to the drastic changes an individual experiences after a stroke, they are often faced with a new perspective of themselves. For some, it can be very difficult to become confident in their new self because they feel as if they have let themselves down because of the stroke (Taule & Raheim, 2013). Many stroke survivors develop a new sense of self which can be difficult to understand as they continuously compare themselves to their old self. By having a new perception of themselves, it creates obstacles for the individual and their family to overcome (Taule & Raheim, 2013). It has been recommended to work on a survivor's perception of themselves to ensure their quality of life does not deteriorate, as researchers have noted lower self-esteem among stroke survivors (Taule & Raheim, 2014). Understanding the changes an

individual faces after a stroke will ensure they are able to become comfortable with their new living situation (Taule & Raheim, 2013).

Although there is a lot of stress on the family, caregivers, and healthcare team, there is also a lot of unfamiliarity regarding this new experience for the individual who had a stroke (Strum et al., 2002). Kitzmuller et al. (2013) explored the significance of long-term influence of bodily changes on the perception of their selves after stroke. In order to understand the experiences of these individuals, interviews were used for data collection. To be included in this study, participants needed to meet the following criteria: minimum of three years after a disabling stroke, over 16 years old, living at home, and the cognitive ability to give informed consent (Kitzmuller et al., 2013). There were 23 interviews conducted: 17 were with individual stroke survivors, and six were with a stroke survivor and their significant other. There were four themes generated that related to their influence on self-perception which included: 1) living with an altered perception of self, 2) living in a fragile body, 3) increased attention to bodily functions, and 4) living in a body that is not me (Kitzmuller et al., 2013). The researchers highlighted that the themes from the interviews gave important insight and reflection into experiences that is difficult to understand otherwise (Kitzmuller et al., 2013). The researchers recommended that future studies should consider using interviews with the stroke population as it gives the opportunity for these individuals to discuss their thoughts and experiences.

Another study examined the relationship between disability, handicap, and patient perceptions of recovery after stroke using quantitative methods including the London Handicap Scale and Barthel Index (Strum et al., 2002). There were 107 patients who were assessed at 3 and 12-months post-stroke. It was concluded that participants differed in their own perception of recovery. Some participants who were more severely handicapped than others did not show that



they were aware of the severity through the scale (Strum et al., 2002). This study showed how it is difficult to display an accurate perception of recovery without discussing with the individual. Thus, the researchers recommended speaking with these individuals to further understand their perception of recovery through measures such as interviews (Strum et al., 2002). Therefore, this study highlights the importance of listening to individual stories to gain new perspectives, as some information may be missed when quantifying experiences using scales.

### **Quality of Life**

Another important consideration for individuals after a stroke is their overall quality of life. This construct has been studied for years (e.g., Bethoux et al., 1999; Taule & Raheim, 2013) yet research is ongoing due to its importance to stroke recovery. Bethoux et al. (1999) assessed two groups of hemiplegic stroke patients who were either discharged from the hospital fewer than six months ago (Group 1), or more than six months ago (Group 2). Disability was assessed by the Functional Independence Measure (FIM), and quality of life was measured by the Reintegration to Normal Living Index. There were no significant differences in the FIM; however, the Reintegration to Normal Living Index scores were significantly lower in Group 2. Results revealed that scores were significant between groups, which solidified the notion that quality of life was important to address at every stage after stroke, but especially for those who were greater than six months post-stroke (Bethoux et al., 1999). Taule and Raheim (2013) also explored the home recovery quantitatively of eight mild-stroke survivors 6-8 months post-stroke. Extensive interview data were analyzed through an interpretive strategy and systematic text condensation (Taule & Raheim, 2013). The stroke survivors explained how their life changed profoundly in relation to their health, body, and activities of daily living, highlighting how it complicated their daily activities and close relationships. These constructs related to the

importance of overall quality of life which emphasizes the need for ongoing support needed for self-improvement (Taule & Raheim, 2013).

### **Approach to Understanding a Patient's Personal Experiences**

For individuals living with the effects from a stroke, understanding their personal experiences associated with their stroke is important. Specifically, healthcare providers and researchers need to understand their experiences in order to provide and advocate for proper care (Taule et al., 2015). In general, one's personal experiences can be described as knowledge that has been obtained through direct contact, rather than hearing it through another individual or through a technological medium (Rego, 2021). These personal experiences are especially important because in any situation, no one truly understands what happens and how someone feels, except for the individual with that experience. This is important for individuals who have had a stroke because their whole world is disrupted, and no one else is able to fully understand their personal experiences associated with the stroke (Rego, 2021). In order to understand someone's experience, directly speaking to the person and allowing them to explain their own experiences specifically with stroke is essential.

In the literature, the need to use a qualitative lens to further explore and understand one's personal experiences has been highlighted. Most of the research conducted has been through a quantitative lens via surveys (Brajkovic et al., 2009; Chen et al., 2011; Michael et al., 2015; Nicholson et al., 2017; Rimmer et al., 2008). In addition, there has been two studies that have summarized studies that have explored the experiences of those who have had a stroke during different times throughout their life. First, a qualitative meta-synthesis was used to examine the published literature of the experience of those living with effects after a stroke (Salter et al., 2008). This study found five themes which suggested that after a stroke, feelings of loss,

uncertainty, and social isolation are apparent (Salter et al., 2008). Although these findings were revealed, it indicated that stroke survivors can move forward through adaptation towards their own recovery. A second study used a systematic review of qualitative studies to look into stroke survivor's' experiences of physical rehabilitation during their inpatient care (Luker et al., 2015). For this study, negative experiences were reported in all studies in relation to their physical rehabilitation and recommended that future research should focus on genuine patient-centered care and the patient's own preferences. Thus, these two studies in particular highlight the need of further exploring the experiences of stroke survivors at different stages of their care to learn more about their needs and particularly not just during inpatient care. The few other qualitative studies that have been carried out involved structured interviews which used a ranking system for individuals to rank different barriers to rehabilitation on a scale from one to ten (Nicholson et al., 2013; Taule et al., 2015). This emphasizes the need for less structured interactions to speak with stroke survivors about their rehabilitative experiences and any barriers and facilitators they face.

As mentioned in the literature, Northwestern Ontario communities such as Thunder Bay are more susceptible to worse health outcomes (Shurrab et al., 2017). This is due to fewer readily available resources, less access to services, along with the limited number of healthcare professionals and less time spent with them (Shurrab et al., 2017). As there is limited research specific to Thunder Bay, a remote region of the province, a need to speak with stroke survivors about their experiences exists to fill this gap in the literature. In addition, due to the recent COVID-19 pandemic, there is also limited research regarding the stroke and rehabilitation experience during this time, suggesting that an exploratory study is both timely and warranted.

## **Chapter Two: Methodology**

### **Purpose of Study**

The purpose of this qualitative constructivist study was to explore the personal stroke and rehabilitation experiences of older adults with chronic stroke living in Thunder Bay using semi-structured interviews. This is important because in Thunder Bay, compared to Southern Ontario and other more populated areas, there are fewer stroke-specific services and more limited access (Donio et al., 2019). To date, it is unknown how these differences affect stroke recovery (Donio et al., 2020). It is hoped that the outcomes of this research can be used to optimize the recovery experiences for future survivors in this region from a wellness perspective.

### **Study Design**

Qualitative research consists of multiple meanings, flexible designs, purposive sampling, and non-numerical data (Kowalski et al., 2018). This constructivist qualitative study used a descriptive approach (Kowalski et al., 2018) which involves exploring a phenomenon with no attempt to connect the information or explain the outcomes (Kowalski et al., 2018). Because this study was qualitative in nature, it allowed participants to expand on their personal experiences related to their stroke and rehabilitation processes to gather an exploratory account of their journeys. With regards to philosophical worldview, a constructivist approach (Kowalski et al., 2018) was taken throughout the study development, implementation, and interpretation. This is based on the idea that multiple realities exist, and that meaning is varied and complex depending on context and experience (Creswell, 2014). As a result, I adopted a stance where there was no distinct set of emotions or outcomes, and therefore feelings and experiences were subjective (Kowalski et al., 2018). This approach was particularly important during the data collection and analysis phase. I focused on allowing the participants to generate their own interpretations to the

questions throughout the interview and guided them as needed (Kowalski et al., 2018). During the data analysis phase, myself and the principal investigator (TK) also applied this approach by using the data to extract common themes that emerged organically from the data and did not use any preconceived notions from any of the researchers own point of views (Kowalski et al., 2018). This process is explained in more detail below.

### **Positionality of the Researcher**

Positionality can be defined as recognizing one's orientation and research stance (Jafar, 2018). This is particularly important in qualitative research to recognize and be aware of. I did recognize my own position (i.e., a young, educated, and active Indigenous female) which could have influenced the research study via data collection, analysis, and interpretation of the findings (Lincoln & Guba, 1985). Although this study topic fell within my academic background and knowledge, I had not lived the experience of having a stroke and did not compare to their age. This could have impacted the research findings. In service of transferability and transparency, I provided insight into how awareness of my own positionality was maintained through a detailed account which is described below in the *trustworthiness* section.

### **Participant Inclusion and Exclusion Criteria**

There were no specific inclusion criteria related to gender, sex, or age characteristics to participate in this study. Participants were included if they were diagnosed by a physician with having a stroke, were discharged from the hospital, and had their most recent stroke more than six months ago (chronic stroke) before starting the study. Participants must have also felt comfortable and willing to engage in an interview regarding their stroke and needed to be able to give informed consent. Individuals saw a series of pre-screening questions in the information letter which ensured they met the criteria and were confident to participate in an interview.

Participants who had a TIA as their main diagnosis were excluded, as the side effects of this type of stroke may not last long or may not cause permanent damage, and even go unnoticed in some cases (Frizzel, 2005). Those who had a stroke less than six months ago were also excluded from the study as they may not have yet reached the steady state of recovery that often occurs about six months after a stroke (Sun et al., 2015). Due to the disparities in health services between Northwestern and Southern Ontario (Donio et al., 2019), only those living in the city of Thunder Bay were included in the study. The city of Thunder Bay includes boundaries at the following areas: Terry Fox monument, Townline Road, Twin City Cross Roads, and Neebing township (Beaulieu et al., 2021). All individuals were also required to have access to a telephone or Wi-Fi compatible device, speak English, and feel comfortable answering questions related to their stroke experience.

As this study was conducted in a completely remote fashion to adhere to social distancing protocols due to the COVID-19 pandemic, participants who did not have access to a telephone or Wi-Fi compatible device were not able to participate.

### **Recruitment Process**

Purposive sampling was used with the intent of choosing participants that directly related to the proposed research study (Kowalski et al., 2018). This technique was used at St. Joseph's Care Group along with other affiliated clinics in Thunder Bay which included the Northwestern Ontario Regional Stroke Network, Outpatient Neurology Rehabilitation at the St. Joseph's Care Group, 55+ Center, and Canada Games Complex. In addition, snowball sampling was used whereby participants in the study or who participated or had seen the poster were asked to inform other prospective participants. The sample size was justified using the process of data saturation, which is the most commonly used method in qualitative studies (Fusch & Lawrence, 2015). This

process was reached when the following three criteria were met: 1) there was enough information to replicate the study, 2) no new information was being attained, and 3) when further coding was no longer feasible (Guest et al., 2006; O'Rielly & Parker, 2012; Walker, 2012).

Based on the few qualitative studies that had been conducted regarding stroke survivors, 10 to 15 stroke survivors was the expected range needed for data saturation (Eng et al., 2014; Taule et al., 2015; White et al., 2020).

### **Participant Demographics**

In order to protect the participant's anonymity and confidentiality throughout this report, each participant was given a pseudonym which will be used for the rest of the report when describing the participants. The following information was obtained from all 10 participants when discussing their demographic information. Henry was a 57-year-old male who had a hemorrhagic stroke five years ago and completed all rehabilitation options available. Nancy was a 65-year-old female who also had a hemorrhagic stroke five years ago in which all rehabilitation options were completed. Samuel was an 80-year-old male who had an ischemic stroke two years ago where all rehabilitation had been completed. Victor was a 77-year-old male who had a stroke (did not know what type) 10 years ago in addition to other complications which hindered his ability to complete stroke specific rehabilitative services. Frank was also a 77-year-old male who had a stroke (did not know what type) four years ago in which all rehabilitation was completed. Dorothy was a 71-year-old female who had a hemorrhagic stroke three years ago in which all rehabilitation was completed. Paul was a 61-year-old male who had an ischemic stroke 12 years ago and all rehabilitation had been completed. Evelyn was also a 61-year-old female who had an ischemic stroke five years ago and had completed all rehabilitative options. Irene was a 64-year-old female who had a stroke (did not know what type) one year ago in which all rehabilitative

options were also completed. Finally, Eli was a 79-year-old male who had a hemorrhagic stroke nine years ago where all rehabilitative options had been completed. All participants were comfortable in conducting an interview over the telephone and did not have any speech impediments.

In total, 10 participants completed the study. The age of participants ranged from 57-80 years of age (Mean [ $M$ ] = 69.2, *standard deviation* [ $SD$ ] = 8.6), and included four female (40%) and six male stroke survivors (60%). When asked how many years ago their stroke was, the answers ranged from 1-12 years ago ( $M = 5.6$ ,  $SD = 3.6$ ). Forty percent of participants had a hemorrhagic stroke, 30% had an ischemic stroke, and 30% did not know what type of stroke they had. The demographic data can be seen below in Table 1.

**Table 1**

***Participant Demographic Data***

<b>Participant Demographics</b>	<b>Frequency</b>	<b>(%)</b>
<b>Gender</b>		
Male	6	60
Female	4	40
<b>Age (years)</b>		
50-59	1	10
60-69	4	40
70-79	4	40
80+	1	10
<b>Type of Stroke</b>		
Hemorrhagic	4	40
Ischemic	3	30
Did not know	3	30
<b>Time Since Stroke (years)</b>		
1-4	4	40
5-9	4	40
10+	2	20

*Note.* This table shows demographic data that was collected from the 10 participants.



A summary of each of the 10 participant's rehabilitative journeys that were extracted from the interview notes can be seen in Table 2. To compare between participants, rehabilitation processes and milestones were organized by time for each participant, where data were available.

**Table 2**

*The Rehabilitative Journey of Sample Participants*

	Mode to First Point of Care	Hospital Admission	Hospital Discharge	Hospital Discharge	Rehab Began	End of formal rehab	Beginning of rehab on own
	0-1 hour	1 hour – 24 hours	1 day – 7 days	7 days – 2 weeks	2 weeks – 1 month	1 month – 6 months	6 months +
Henry	Drove self to hospital	Admitted to hospital		Released from hospital	Admitted to rehab center		Ex. and Sp.
Nancy	Ambulance to hospital	Admitted to hospital	Released from hospital		Began rehab at center		Ex. and Sp.
Samuel	Ambulance to hospital	Admitted to hospital			Released from hospital	Returned home	Ex.
Victor			Had heart attack surgery	Returned home	Diagnosis of stroke		Ex.
Frank	Ambulance to hospital	Admitted to hospital	Released from hospital				Ex. and Sp.

Dorothy	Family took to hospital	Admitted to hospital		Released from hospital	Admitted to rehab center	Released from rehab center	Ex.
Paul	Ambulance to hospital	Admitted to hospital					Ex. and Sp.
Evelyn	Family took to hospital	Admitted to hospital	Released from hospital				Ex. and Sp.
Irene	Ambulance to hospital	Admitted to hospital		Returned home		Began rehab at center	Ex. and Sp.
Eli	Ambulance to hospital	Admitted to hospital	Released from hospital				Ex. and Sp.

---

*Note.* This table shows the individual rehabilitative journeys of the sample. *P.* is used to define participant; *rehab* is used to define rehabilitation; *Ex.* is used to define that the participant is exercising; and *Sp.* is used to define that the participant is seeing a specialist(s). P. 04 had a unique experience as they did not realize a stroke had occurred due to other complications with heart attack surgery. All participant names in this table are pseudonyms to protect participants anonymity and confidentiality.

## **Procedures**

After receiving approval from the Research Ethics Board at Lakehead University (1468765) and St. Joseph's Care Group (2022005), the recruitment process began. Recruitment and data collection occurred from April to June of 2022 and all interviews were conducted between business hours (9 a.m. – 5 p.m.) as this was the most convenient time for both the participants and student researcher. All participants chose to conduct the interview over the telephone, rather than a Wi-Fi compatible device when offered both options. Before the interview began, the student researcher obtained verbal consent through the telephone script pertaining to the guidelines in the consent form. Once consent was given, the interview was then completed by following the interview guide.

### ***Semi-Structured Interview***

A semi-structured interview was used to gather the participant's ideas and thoughts around their experiences throughout stroke recovery. The interview guide was developed into five different sections which included: introductory demographic questions, post-stroke life experiences, rehabilitation after stroke in Thunder Bay, barriers and facilitators to rehabilitation and exercise, and questions regarding the COVID-19 pandemic to see if it had impacted their rehabilitation and exercise (Eng et al., 2014; Lee & Klarner 2021; Taule et al., 2015). The interviews were semi-structured, in which the interview guide consisted of some questions, but there was room for participants to expand on their experiences, depending on how much the participant wanted to share (Guest et al., 2006). Open ended questions were used to allow the participants, in their own words, to elaborate on their experiences. Each interview ranged from 30 to 60 minutes, depending on how much each participant wanted to share and were audio-recorded with permission from all participants.

## **Data Analysis**

Descriptive statistics and visual inspection were used to analyze the age, gender, number of strokes, type of stroke, and the rehabilitation journey for the participant sample. The interviews were transcribed verbatim and further analyzed thematically using a combination of inductive and deductive content analysis approaches (Kowalski et al., 2018).

### ***Deductive Content Analysis***

Deductive content analysis was used to organize two main categories in line with the study purpose (Kyngas & Kaakinen, 2019). The interview guide allowed participants to discuss two different stages of their experience with stroke: actual stroke experience and the stroke rehabilitation journey. Themes were then further generated inductively and placed under each category.

### ***Inductive Content Analysis***

Inductive content analysis was used to ensure there were no presumptions regarding the themes generated and that the findings were grounded in the transcribed data (Kowalski et al., 2018). In order to analyze the interview data, NVivo software (NVivo<sup>®</sup>, Melbourne) was used. NVivo<sup>®</sup> has been shown to work well with a variety of research designs, specifically thematic analysis, which was the approach used for this study (Zamawe, 2015). Zamawe (2015) concluded that NVivo<sup>®</sup> has a high level of accuracy and can speed up the analysis process.

A six-phase guide was used to conduct this type of analysis and ensure accuracy of the inductive content analysis process (Braun & Clarke, 2006). The first step was to become familiar with the data which was done by transcribing the interviews and further reading the transcripts multiple times (Elo et al., 2014). Next, I read and looked at the data to begin to recognize common ideas and words on NVivo to generate the initial codes (Zamawe, 2015). From this

initial coding step, 60 codes were generated with these data and were generally organized within the two categories. This was an iterative process where the common ideas were generated over several reviews of the interview transcripts after a coding process was established. This coding process was determined by myself and the principal investigator where it was decided that any quotations that were relevant to or captured something about the research question would be included, rather than only using a specific word (Maguire & Delahunt, 2017). Open coding was used, meaning there were no pre-set codes, but the codes were modified as the process evolved (Maguire & Delahunt, 2017). The third step was to search for themes which was completed with the nodes from NVivo (Zamawe, 2015). Themes were generated using a combination of both participant quotations and stand-alone phrases to enhance the understanding of the themes for the reader. Once the initial themes were generated, the next step was to review the themes with other members of the research team, including the principal investigator and two committee members (EP, PS). This was done multiple times and also included moving backwards through the previous steps to ensure the data were represented accurately. The themes were then defined and wrote-up in the final document once all members of the research team were in agreement.

### **Trustworthiness of the Data**

As a qualitative research design was used, addressing the trustworthiness of the data was needed to ensure the overall quality of the study. Lincoln and Guba (1985) found four strategies to assess the trustworthiness which included credibility, confirmability, dependability, and transferability. In order to establish credibility, I needed to be confident in how accurate the data related back to the purpose of the research study (Elo et al., 2014). This was achieved by always referring to the purpose statement when determining codes and themes. In this study, credibility was enhanced as myself, the principal investigator, and a committee member (EP) developed an

interview guide (Eng et al., 2014; Lee & Klarner 2021; Taule et al., 2015) that was tailored towards the purpose of the study, followed ethical guidelines, and engaged in member checking during the interviews (i.e., summarizing and repeating ideas to participants; Birt et al., 2016). Member checking allowed myself to verify with the participant what they had said and allowed the participant the opportunity to expand or clarify any points made. The next component was confirmability, which is the degree to which the findings are consistent and can be repeated across and among participants, and other researchers during the analysis phase (Connelly, 2016). This was established by both myself and the principal investigator as both took part in the inductive content analysis phase separately. By doing this, it minimized bias and allowed the findings to be rooted within the participants answers and not the researchers' beliefs (Merriam & Tisdell, 2015). During the thematic analysis phase, a member of the committee (EP) also reviewed transcripts, generated codes, and discussed themes with myself to ensure confirmability. An audit trail was also used to show the steps and procedures that led to the final conclusions and outcomes of the study (Merriam & Tisdell, 2015). Dependability or stability referred to the state of the data over time under different conditions (Elo et al., 2014). This strategy was reinforced throughout the data collection and data analysis period by having regular debrief sessions with the principal investigator to reflect on and record any bias that I may have had throughout the interviews. I also was able to adapt throughout each interview by listening to each participant to understand how comfortable they were and how much information they wanted to share. As a semi-structured interview guide was chosen, this allowed for participants to have more freedom in answering the questions (Elo et al., 2014). The final strategy was transferability, which was defined as extrapolation, meaning that the findings could be transferred to other similar situations (Elo et al., 2014). I included all the relevant information,

including a descriptive account of the data in the final report to allow for others to deem whether the findings can be transferred to others research interests. For example, other remote areas in Westernized countries may be interested in the findings.

## Chapter Three: Findings

In this chapter, I will describe the findings in detail. This will begin with participant demographics and be followed by the descriptions of the themes and subthemes which are represented both schematically and with supporting quotes.

### Overview of Themes and Subthemes

In line with the study purpose, two distinct categories were used to group the themes and subthemes. The two distinct categories included: 1) *actual stroke experience* and 2) *the rehabilitation journey*. In total, six main themes and eight related subthemes emerged from the analysis. In the following sections, descriptions and context for each theme and subtheme, within the two categories, will be given.

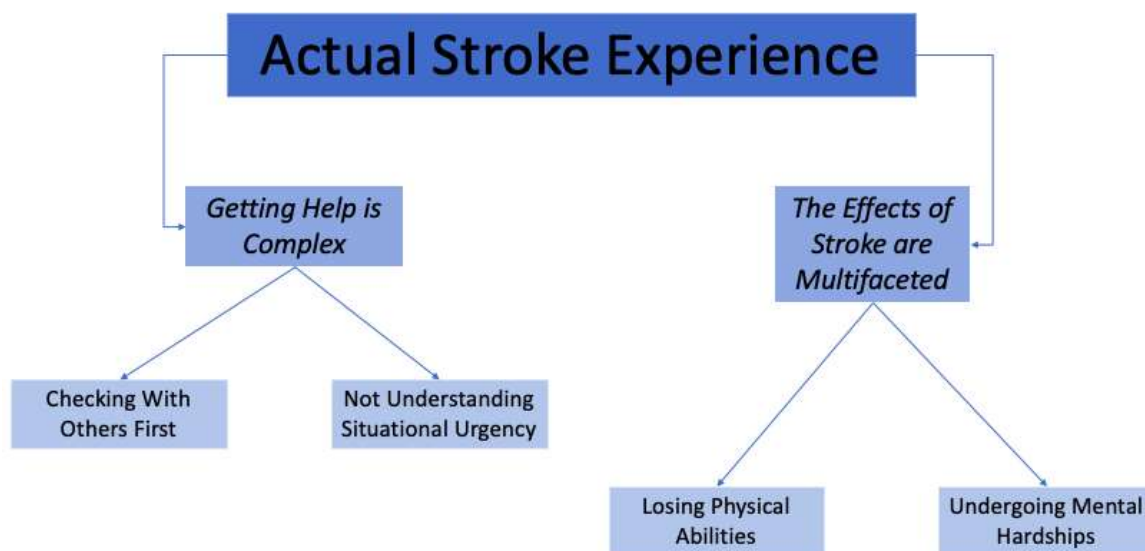
### Actual Stroke Experience

The first category had two overarching themes, along with four related subthemes. These included: 1) *Getting help is complex* (i.e., checking with others first; not understanding situational urgency); and 2) *The effects of stroke are multifaceted* (i.e., losing physical abilities; undergoing mental hardships). A schematic representation of the generated themes and subthemes for this category can be seen below in Figure 1.



**Figure 1**

*Themes and Subthemes Generated from Category One: Actual Stroke Experience*



*Note.* This figure provides a visual representation of the themes and subthemes that emerged from the interviews in category one.

***Getting Help is Complex***

During each of the interviews, participants described what happened once they realized they had had a stroke, and how they got to the hospital. Most were transported to the hospital by ambulance. Many noted that this was not a simple process because they did not realize what was happening to them. Several shared that they needed convincing by a loved one to get help at the time but were grateful for this after the fact. This idea of complexity was evident as many of the participants did not call emergency services when they thought something was wrong. Instead, most of the participants had to speak with someone else before they made any decisions, and many found it difficult to come to terms that something was wrong. This created a complex situation for these participants as they had to take other steps before getting help and may have wasted valuable time as a result. Two related subthemes emerged in relation to this theme

including *checking with others first* and *not understanding situational urgency*; both were highlighted by nearly all participants and made getting help difficult. Supporting quotes representing the subthemes can be found below, and for additional quotes refer to Tables 3 and 4.

**Checking With Others First.** When participants were telling their stories about receiving help before going to the hospital, one commonly mentioned concept was needing to verify stroke symptoms with someone else. This included reaching out to one’s partner, a son or daughter, friends, and even one’s boss before making any decisions for themselves (e.g., calling for help).

“[W]e have a daughter that is a physician in [city]... So my husband said ‘I’m calling her’ ... and she said, ‘[P]ut mom on the phone.’ So I went on the phone and after finishing talking to her for a few minutes, she said, ‘Mom, I think you should listen to Dad. You should go to the emergency. You are not sounding like yourself at all. There’s something missing in your conversation.’” [Dorothy]

Most of the participants noted feeling “different” than normal when their stroke had occurred, but they could not figure out what was wrong and were not overly concerned. This is when most of the participants reached out to someone else to see if they noticed anything concerning. Generally, the other person, although they may not have known it was a stroke, did raise awareness of the situation’s severity and helped the individual make the decision to get help. In many cases, participants stated that this may not have happened otherwise.

**Not Understanding Situational Urgency.** Once participants decided that they needed to go to the hospital for help, many noted that this was not a straightforward process. Most of the participants shared it was not as simple as calling emergency services as soon as they realized something was wrong. Participants either wanted to wait until the symptoms improved or did not

want to acknowledge the urgency of the situation, even after verifying with someone else that something was wrong.

“She [my daughter] called the ambulance right away and [if it was not for] my daughter, [if she] wasn't there, I probably [would not have called 911] because my wife has passed and I had nobody else to talk to if she wasn't there. I don't know what the hell I would have done. I probably wouldn't have done anything. I would have just sat down... until I was okay. I don't know.” [Frank]

Finally, most participants decided to call emergency services, but others had a family member drive them to the hospital, or even drove themselves after several hours. Many participants spoke about wanting to change how they approached seeking help in hindsight knowing now that it was an emergency.

Table 3

*Quotes Supporting Theme 1: Getting Help is Complex*

<b>Checking With Others First</b>
<ul style="list-style-type: none"> <li>• “[W]e have a daughter that is a physician in [city]... So my husband said ‘I’m calling her’ ... and she said, ‘[P]ut mom on the phone.’ So I went on the phone and after finishing talking to her for a few minutes, she said, ‘Mom, I think you should listen to Dad. You should go to the emergency. You are not sounding like yourself at all. There’s something missing in your conversation.’” [Dorothy]</li> <li>• “... the next morning, I just went to get out and the dog was on the bed and I said, ‘No Kansas, let’s get up.’ ... And then, as soon as I said that, I [thought] ‘Oh, my speech seems... kind of funny, like weird.’ And so, then I said to my husband, ‘Is my speech funny? Am I slurring?’ [He said] ‘Yeah, you’re slurring.’ I thought ‘Oh, I’m having a stroke. Take me to hospital.’” [Evelyn]</li> <li>• “...but when I tried to get out of the car, I was instantly sick. Like, I was vomiting and diarrhea and I couldn’t stand up. [I] had no strength in my legs. So he [my husband] came around, got me in the other side of the car and drove me home so [my daughter] could see me, because she’s a nurse. And he thought, you know, ‘[S]he’ll know what’s going on.’ But she just looked at me and said, ‘[N]o, you need to go to the hospital.’” [Irene]</li> </ul>
<b>Not Understanding Situational Urgency</b>
<ul style="list-style-type: none"> <li>• “And ironically enough, I got in my car and drove myself. It was an automatic car. I lived way out at the time... which apparently also is not uncommon. Apparently, people that live out in the country have a tendency to drag themselves in rather than calling an ambulance and get the volunteer services, or whatever else and [have] no thoughts whatsoever that [it might be] a stroke.” [Henry]</li> <li>• “She [my daughter] called the ambulance right away and [if it was not for] my daughter, [if she] wasn’t there, I probably [would not have called 911] because my wife has passed and I had nobody else to talk to if she wasn’t there. I don’t know what the hell I would have done. I probably wouldn’t have done anything. I would have just sat down... until I was okay. I don’t know.” [Frank]</li> <li>• “And then some of my friends came to the party... [they said] I was asking them who they were and I just thought that was all bizarre, ... We got home after the party and my husband said ‘I’m taking you to the emergency because you’re not looking good, and you’re not sounding normal at all.’ So, and I was like, ‘I’ll go to the emergency tomorrow’ and he said, ‘No, I think I should take you now.’” [Dorothy]</li> </ul>

*The Effects of Stroke are Multifaceted*

As participants were describing their experience with stroke, the effects that were associated with having a stroke were also shared and highlighted as burdensome. These effects were something they could not forget due to the impact it had on them immediately and further

into their everyday life and well-being. Participants described how the physical effects left them feeling shocked and afraid which then led to significant mental hardships as the reality of having a stroke settled in. Many noted that even after coming to terms with the physical limitations, the mental hardships still continued, especially when wanting to improve abilities or regain functions such as memory. The loss of physical abilities and mental hardships were often spoken about together, showing the complexity of the effects after a stroke. Two subthemes emerged from this theme which included *losing physical abilities* and *undergoing mental hardships*.

**Losing Physical Abilities.** The physical effects from the stroke were most often what participants described in detail when asked about their experience. For example, losing some type of physical ability (e.g., sensation in arm/leg, not being able to move their face, not being able to get up off the floor) was described by many as what they woke up to following their stroke; this experience left a lasting impression.

“[I] didn’t even think [a] stroke [had happened] initially, but woke up and my right arm was completely, completely numb. But, in a strange way. Not comparative to when you sleep on something. But not the same in the fact that as I woke up [I] could feel it. I always could feel it. I just couldn’t move it. And as I was explaining after, it was you know, [my] brain didn’t recognize it as [my] arm anymore. So part of me... I knew it was my arm, whatever area of the brain... it was very confusing.” [Henry]

As a result of the loss of physical abilities, many participants felt afraid and began to lose hope as it was difficult to understand what was going on. These feelings were exacerbated when they were in the hospital and asked to perform tasks such as walking; most participants could barely get out of bed. This was difficult for all participants as they described they felt as if their independence was being taken away. According to participants, losing physical abilities in

relation to the stroke experience such as walking or being able to use a part of their body was life changing and difficult to come to terms with.

**Undergoing Mental Hardships.** Another concept that was mentioned often when describing their actual stroke experience was undergoing mental hardships. For example, having mental fatigue, losing mental capabilities such as memory, and having heightened emotions were noted across all participants.

“That’s one thing ... I can’t always measure is the the mental things. Like, sometimes I just go to to reach for a word or try to remember something from two seconds ago and it’s it’s just not there. Or sometimes I still say the wrong name. Like, I’ll be saying, you know, ‘I need to get a spoon,’ but really, I need to get a fork. And every now and then, I still go down that nasty little road. My husband will go ‘That’s a fork.’ I went, well, ‘That’s what I said.’ Not perfect, but it is what it is.” [Nancy]

These were particularly highlighted as experiences that the participants had when they were in the hospital undergoing acute care and described how they were feeling mental and emotional hardships they had never experienced before. As stroke was an unfamiliar experience for most, it was something participants wanted to continue to speak about with the interviewer due to the overwhelming emotions. One major event that was noted as a contributor to mental hardship was having one’s driver’s license revoked. Interestingly, all participants spoke about the moment this occurred and how it felt as if a piece of their freedom was being taken away.

“They took my driver’s license away. And that was also hard for me to take because I guess I wasn’t realizing how bad it [the stroke] was. I just thought that it was mean and they took my license away for no good reason, you know? They could tell that I had trouble seeing... which was true.” [Dorothy]

Table 4

*Quotes Supporting Theme 2: The Effects of Stroke are Multifaceted***Losing Physical Abilities**

- “[I] didn’t even think [a] stroke [had happened] initially, but woke up and my right arm was completely, completely numb. But, in a strange way. Not comparative to when you sleep on something. But not the same in the fact that as I woke up [I] could feel it. I always could feel it. I just couldn’t move it. And as I was explaining after, it was you know, [my] brain didn’t recognize it as [my] arm anymore. So part of me... I knew it was my arm, whatever area of the brain... it was very confusing.” [Henry]
- “At the very beginning, pretty much I was bedridden at the very, very beginning. I couldn’t get up on my own. I couldn’t move my right side at all. My talking was very, very slurred. My face was all drooped down.” [Nancy]
- “So, until I had some energy to actually start doing some exercise, well not exercises for real, but I was just expected to do a little bit of walking along the hallway in the hospital and I couldn’t even do that.” [Dorothy]
- “At first... they couldn’t get ... my left leg to work [and] my left arm to work, so I was paralyzed basically on the left side.” [Eli]

**Undergoing Mental Hardships**

- “Due to the fact of me living way out in [location] ... and not having any family support or anybody to come, [I] lost my driver’s license at that point in time, which is apparently normal protocol. So, no bus service out there. So now I’m starting to panic. They’re talking about releasing me and I’m saying, ‘I don’t have full use of my arm.’ You know? And then, started getting numbness in my leg after. Started getting numbness in my face and it was like, ‘You’re panicking because okay, now... you’ve done all these tests. Yes, you’ve had a severe stroke. You have no driver’s license. You drive for a living.’ All of a sudden, boom! You’re sitting there panicking and you lost everything.” [Henry]
- “That’s one thing ... I can’t always measure is the the mental things. Like, sometimes I just go to to reach for a word or try to remember something from two seconds ago and it’s it’s just not there. Or sometimes I still say the wrong name. Like, I’ll be saying, you know, ‘I need to get a spoon,’ but really, I need to get a fork. And every now and then, I still go down that nasty little road. My husband will go ‘That’s a fork.’ I went, well, ‘That’s what I said.’ Not perfect, but it is what it is.” [Nancy]
- “No, nothing especially for anything physical. If I have any effect from it [the stroke] I would say it’s a little bit of mental loss.” [Samuel]
- “They took my driver’s license away. And that was also hard for me to take because I guess I wasn’t realizing how bad it [the stroke] was. I just thought that it was mean and they took my license away for no good reason, you know? They could tell that I had trouble seeing... which was true.” [Dorothy]
- “The emotions, like, I still get like that too. I seem to cry or get excited faster. Like ...when I first had the stroke, oh my God, [when I was] in the hospital I would just start crying. I thought ‘What is wrong with me?. I’m just crying.’ And then, then somebody came in to come visit ...and I would just look at them and I would start crying ... it just was overwhelming.” [Evelyn]

## The Rehabilitation Journey

The second category, the rehabilitation journey, had four overarching themes (along with four subthemes). These included: 1) *Losing rehabilitation services during the COVID-19 pandemic*; 2) *Overcoming hardships, but not alone* (i.e., positive encouragement to help make progress; needing support after secondary diagnosis); 3: “[I]f you don’t use it, you lose it”: *Rehabilitative success is based on one’s actions* (i.e., determination and open-mindedness about rehabilitation; forced independence leads to next rehabilitation steps); and 4: “[L]ook at me now”: *Taking pride in one’s successes*. Descriptions and examples for each theme and subtheme are below. A schematic representation for this category can be seen below in Figure 2. Supporting quotes can be found throughout the descriptions and additional quotations can be found in Tables 5 – 8.



Figure 2

*Themes and Subthemes Generated from Category Two: The Rehabilitation Journey*

*Note.* This figure provides a visual representation of the themes and subthemes that emerged from the interviews regarding the rehabilitation journey.

*Losing Rehabilitation Services During The COVID-19 Pandemic*

When asked how the COVID-19 pandemic affected their recovery, one concept that emerged across all the participants was losing their access to rehabilitation services. This was described in a negative context whereby the participants had a difficult time adjusting to having no rehabilitation services after being dependent for several years. This affected participants physically; many believed they had taken several steps backwards in relation to their progress as it was difficult to make the same improvements independently from home.

“Well, there was the period of time or periods of time where I wasn’t able to go for physiotherapy, for example. I felt that I was making wonderful progress with my

physiotherapist and then I had to stop seeing him. And I really think, and I still do to this day, I believe that that was detrimental to my recovery.” [Henry]

Participants also mentioned how it affected them mentally. This was mainly due to the lack of socialization experienced without consistent rehabilitation programming. Several participants mentioned missing socialization with their healthcare practitioners, those who worked in the clinics, and other patients who were undergoing care or participating in the exercise classes. Those who had a stroke during the pandemic or just before the pandemic (four participants) also were denied any rehabilitation programming due to pandemic restrictions which also hindered their ability to make any physical or mental improvements. According to these participants, the loss of rehabilitation services during the COVID-19 pandemic impacted their stroke rehabilitation in a negative way.

“Since the um pandemic I was going to the [location] stroke meeting support group but they haven’t been able to have live in-person meetings, obviously for the last two and some years. They do have some programs that I don’t usually participate in because I pretty much [have] done all the programs in the past. But...it’s nice for people to be able to get into that group and share thoughts or just even like, the social experience to know that people are out there and people are doing this ...sharing the same problems, so that [group program] will be starting again hopefully.” [Nancy]

Table 5

*Quotes Supporting Theme 3: Losing Rehabilitation Services During The COVID-19**Pandemic.*

<b>Losing Rehabilitation Services During The COVID-19 Pandemic</b>
<ul style="list-style-type: none"> <li>• “Well, there was the period of time or periods of time where I wasn’t able to go for physiotherapy, for example. I felt that I was making wonderful progress with my physiotherapist and then I had to stop seeing him. And I really think, and I still do to this day, I believe that that was detrimental to my recovery.” [Henry]</li> <li>• “Since the um pandemic I was going to the [location] stroke meeting support group but they haven’t been able to have live in-person meetings, obviously for the last two and some years. They do have some programs that I don’t usually participate in because I pretty much [have] done all the programs in the past. But...it’s nice for people to be able to get into that group and share thoughts or just even like, the social experience to know that people are out there and people are doing this ...sharing the same problems, so that [group program] will be starting again hopefully.” [Nancy]</li> <li>• “I was supposed to do that [exercise] myself after my stroke, but with the virus coming in, everything shut down, so it didn’t happen... I got to have one session over there [rehabilitation facility] with the nurse practitioner and chatted and then the next move was going to be to come and start taking some physical exercise in their area ... but it never happened.” [Samuel]</li> <li>• “That [lockdown] was really bad...the [gym] is, has quite a few shutdowns over this period of time. I mean, the first batch was like, just about a whole year. Oh my gosh ... that was a little tough.” [Victor]</li> <li>• “I was exercising and then, you know, everything closed down because [of] the pandemic...so I started going [on] that treadmill and like, now I just actually injured my knee. So, I basically haven’t done anything for about a month and a half, and I’m just getting X-rays and also the ultrasounds, but but I need to get back to exercise because I gained my weight back and I know I need to. Like, you know, when I had the stroke, I was really good.” [Evelyn]</li> </ul>

*Overcoming Hardships, But Not Alone*

When participants were asked about their journey through rehabilitation, one concept that was often repeated was constant positive support that was received during their care. This ranged from formal support from healthcare providers who went above and beyond to help them make progress, to informal support from family, friends, and coworkers who were there cheering them on and helping in any way they could. It also included other patients who motivated one another

to keep pursuing rehabilitation. The participants mentioned many times how having someone there who cared for them made a difference in their journey. Many hardships were noted by the participants as a result of the stroke, but all participants highlighted many times the support that was received to help them overcome these hardships. Two subthemes emerged from this theme and included *positive encouragement to help make progress* and *needing support after secondary diagnosis*.

**Positive Encouragement to Help Make Progress.** When reflecting on the successes and challenges they had overcome, one concept that was mentioned by all participants many times was owing their successes to others. This was due to the overwhelming positive encouragement that was received from family, friends, healthcare providers, and other stroke survivors undergoing rehabilitation throughout their journey.

“I think people, more than anything, uh made that the world of difference to me as a patient...being helped and being taught how to do things properly... I don't think I found one person that... did anything that made me feel uncomfortable in any way, shape, or form.” [Frank]

Many participants described how happy they were with their progress because they could remember the people who went above and beyond to encourage them to keep pushing through. Most of the participants who had the opportunity to undergo group-based rehabilitation classes (i.e., fitness or group sharing) also mentioned how beneficial it was to have positive encouragement from people going through the same experience as it allowed them to empathize with one another. Many participants also mentioned that being with others undergoing similar situations provided them with a personal push to keep participating in exercise and rehabilitation.

**Needing Support After Secondary Diagnosis.** In addition to the ramifications associated with a stroke, all participants encountered other injuries or diseases (i.e., cancer, heart attack, broken hand, brain injury, dementia) during their stroke rehabilitation journey. For a lot of the participants, this was a challenging time as they became frustrated due to needing more rehabilitation services related to their secondary diagnosis. Participants had a relatively easy experience finding support: usually a physiotherapist or specialized clinic depending on the nature of the injury or disease. Participants mentioned multiple times how thankful they were for finding these healthcare providers and how much support they provided them during this challenging time.

“And then [brain injury service], did a lot of work with me too... They’ve been really good for me, and they actually do still work with me... They were probably one of the best as far as far as having helped me the most. Yeah, they still work with me every day. I have [brain injury service]. If I need anything, they’re always there for me.” [Paul]

It was also mentioned by many participants that a lot of the healthcare practitioners began helping the individual with stroke-related conditions once the other condition was being monitored. Participants highlighted that although stroke is a catastrophic event, there are also many other ramifications that come afterwards that may not necessarily be stroke related. Therefore, the support one finds for those subsidiary conditions is also essential to one’s stroke rehabilitation success.

Table 6

*Quotes Supporting Theme 4: Overcoming Hardships, But Not Alone.*

<b>Positive Encouragement to Help Make Progress</b>
<ul style="list-style-type: none"> <li>• “I actually was able to get up on the elliptical and start being comfortable to use that again. And again, it’s a group of people that are sharing a recovery program...I think for the most part that [being around others] was really, really nice. And you could see the different abilities of people, but you could also sometimes see people whose abilities were getting better... because you don’t always see it in yourself.” [Nancy]</li> <li>• “I think people, more than anything, uh made that the world of difference to me as a patient...being helped and being taught how to do things properly... I don’t think I found one person that... did anything that made me feel uncomfortable in any way, shape, or form.” [Frank]</li> <li>• “I found a gentleman that was, he was from [a non-profit stroke program]. He was coaching us to walk at the [mall]. I found him to be really helpful because he was just really encouraging. He never thought any amount of walking you did was not [good enough]... Then he would tell us about areas in the community that, you know, would be the same as walking at [the mall]. Like, he would say, ‘If you walk from here to here, that would be the same amount as walking at the [mall] program,’ and what not.” [Dorothy]</li> <li>• “The encouragement was a good thing. I still find that [is] a good thing when people are encouraging you to do better, you know? ... That’s really the highlight of my rehab is all the encouragement I got from the, the rehab people.” [Dorothy]</li> <li>• “She [the occupational therapist] made me work. She made me work but it worked out really good and helped me a lot. She’s a smart lady. If it wasn’t if it wasn’t for her [I would have given up]...because it’s easy to just walk away when you don’t want to do it right?” [Paul]</li> </ul>
<b>Needing Support After Secondary Diagnosis</b>
<ul style="list-style-type: none"> <li>• “... I had actually slammed my hand in a car door while I was in the midst of having my stroke at the very beginning. I had um injured a couple of fingers very badly, so fortunately I had a connection at the [local rehabilitation clinic] who I happened to run into and he said, ‘You have to come into the clinic and I’m going to look at that and we’re going to fix it up.’ And he did. He made sure that my finger, not perfectly straight, but it did finally get to be straighter after months of therapy.” [Nancy]</li> <li>• “Well, my daughter’s [trying] to get me to go and do more, but I’m just, I’m sort of tired. I can’t. Like I said, I’ve done a lot...Then I got lymphoma. B-cell lymphoma cancer. Then I went to I went to [a cancer clinic], and I took six months of heavy radiation, or uh heavy chemo. And and then two years of every three months they were giving me injections on my stomach. Well for, for further treatment...So it’s sort of been busy with others... [I’m] just tired.” [Frank]</li> <li>• “And then [brain injury service], did a lot of work with me too... They’ve been really good for me, and they actually do still work with me... They were probably one of the best as far as far as having helped me the most. Yeah, they still work with me every day. I have [brain injury service]. If I need anything, they’re always there for me.” [Paul]</li> </ul>

### **“If you don’t use it, you lose it”: Rehabilitative Success is Based on One’s Actions**

In relation to the rehabilitation journey, participants mentioned how much they had learned during the process, even if it was something they did not want to do. All of the participants expressed that they were frustrated and upset after their initial stroke diagnosis and before beginning rehabilitation; however, many stated that they learned to trust the process and became determined to see results. Many participants explained how it was their own personal choice to pursue rehabilitation in such a positive way and is why they were successful. Towards the end of their programmed rehabilitation journey, all of the participants realized they had to find their own ways to continue rehabilitation in order for it to become part of their lifestyle. Two subthemes emerged from this theme which included *determination and open-mindedness about rehabilitation* and *forced independence leads to next rehabilitation steps*.

**Determination and Open-Mindedness About Rehabilitation.** Based on these participant accounts, being openminded was essential to rehabilitative success. At the beginning of the rehabilitation journey, all of the participants explained how they were apprehensive about beginning any type of rehabilitation because they felt defeated. Through being open-minded, participants said they realized the only way to get better was to begin rehabilitation which is where their determination started. All participants shared how they tried everything that was offered to them with the hopes they would one day reach their goals and get back to what they used to do.

“Well, you know, once I realized what had happened and what was required, I was at their [healthcare providers] mercy. I did everything they asked me to do and some things were truly difficult for me to do, but I tried and even learned some new things. I never said no to anything.” [Dorothy]

Many stated that learning about and using the tools to be successful with the help of others, further allowed them to learn how to do things independently again. According to all participants, being determined and openminded allowed them to learn the tools to be successful in rehabilitation and further take these skills into their everyday lives to practice on their own.

**Forced Independence Can Lead to Next Rehabilitation Steps.** Once participants had reached the end of their programmed rehabilitation, a lot of them shared that they felt lost and were unsure what would be next. They had all reached a point where they had completed the maximum amount of rehabilitation services and were forced to make decisions about what would be next regarding their rehabilitation. This was because healthcare providers told participants there were no rehabilitation options remaining and left the decision with the participants as to what would be next. All the participants quickly realized that it was up to them to ensure their rehabilitation journey did not stop because the programming stopped. They instead found other clinics or healthcare providers who would help them continue or begin to exercise at home.

“No [I was not offered rehabilitation], I figured that [exercise] out on my own. I started going to the pool and I’ve been doing it ever since. Five days a week I’m in the pool at 6:00 in the morning.” [Victor]

When participants spoke about their life after formal rehabilitation, it was always associated with exercise; this was the primary way for them to maintain rehabilitation at home. Participants mentioned how they had to take the initiative themselves because they realized they did not want to cause any further problems (i.e., heart attack, weight gain, another stroke) or lose any of the progress they had made. All participants did partake in exercise in some capacity.



Table 7

*Quotes Supporting Theme 5: “If you don’t use it, you lose it”: Rehabilitative Success is Based on One’s Actions.*

<b>Determination and Open-Mindedness About Rehabilitation</b>
<ul style="list-style-type: none"> <li>• “Anything that they [healthcare providers]... suggested to me, I was totally willing to try, I mean ... I can’t think of anything that I didn’t do. I remember people being in therapy and saying ‘Aw, I don’t want to walk around the block three times a day!’ or something like that. But I mean, I probably did it four times a day just because I was an overachiever and I and I was able to. So yeah, I followed the doctor’s protocol pretty much to a tee.” [Nancy]</li> <li>• “I tried everything they wanted me [to]. Everything they said, I did. Yeah ... you don’t say no to that...you do it [what the healthcare providers say] so it can help you.” [Frank]</li> <li>• “Well, you know, once I realized what had happened and what was required, I was at their [healthcare providers] mercy. I did everything they asked me to do and some things were truly difficult for me to do, but I tried and even learned some new things. I never said no to anything.” [Dorothy]</li> <li>• “Well I’ll just I’ll take anything that comes along ... I like challenges.” [Eli]</li> </ul>
<b>Forced Independence Leads to Next Rehabilitation Steps</b>
<ul style="list-style-type: none"> <li>• “But again, I found everything there [at the hospital] to be really good and it’s once you get released from the hospital... I think they felt there wasn’t a lot of need for follow-up through the hospital. So um, then I was kind of on my own to work through things.” [Henry]</li> <li>• “...I’m just lucky. I think that I was able to find people like that [other rehabilitation services] on my own. I think that [having to find own rehabilitation] is my biggest complaint and the biggest thing that I would want to get better in [city] is you shouldn’t [need to find your own rehabilitation because] you’re sick. You shouldn’t have to go out and find things [rehabilitation] on your own.” [Nancy]</li> <li>• “No [I was not offered rehabilitation]... I just took it upon myself because I had this perfect building here to exercise in. Uh, but I just carried on and I had a membership at the sports [local recreation centre] so I put that on hold.” [Samuel]</li> <li>• “No [I was not offered rehabilitation], I figured that [exercise] out on my own. I started going to the pool and I’ve been doing it ever since. Five days a week I’m in the pool at 6:00 in the morning.” [Victor]</li> <li>• “I keep saying it is too bad that we couldn’t keep that exercise program for heart [and] stroke for people to just continue on, but it’s only for rehab. And then you have to go to like the [local recreation centre] or whatever. You got to do it on your own, but it was it was nice to go there because it kind of felt safe and you would always be learning... I was always nervous if I exercised too hard. ‘I’m going to have another stroke or heart attack.’” [Evelyn]</li> </ul>

### **“Look at me now”: Taking Pride in One’s Successes**

When discussing the participants rehabilitation journeys, there were no questions asking about their successes. Instead, questions about facilitators that made their journey easier. As a result of this question, in addition to other prompts, all participants had at least one story in which they discussed how seeing their own success was a life-changing moment. For example, many participants shared how far they had come from the first day of their stroke and expressed great pride in the progress they had made. There were also a few participants who could remember a singular event in which they experienced success for the first time.

“I was able to walk down the aisle for my son’s wedding, by the way... Yeah. They gave me a cane the day that we were going to go to the rehearsal. I just remember, like, I just wanted to hug and kiss the therapist.” [Nancy]

According to participants, acknowledging these successes were integral for helping them more forward, especially during the more challenging times throughout their rehabilitation journey. Most participants also highlighted how looking back at their successes helped them remain determined.

Table 8

*Quotes Supporting Theme 6: “Look at me now”: The Importance of Taking Pride in One’s Successes.*

---

<b>The Importance of Taking Pride in One’s Successes</b>
<ul style="list-style-type: none"> <li>• “So it was on, you know, a day or two before I started actually, I think it was only a day that I could start lifting my right arm slightly again. And uh I just remember being super excited about that. Like yelling ‘Look, I can lift my arm!’ and the nurse was like, ‘Oh wow, that’s very good.’” [Henry]</li> <li>• “I was able to walk down the aisle for my son’s wedding, by the way... Yeah. They gave me a cane the day that we were going to go to the rehearsal. I just remember, like, I just wanted to hug and kiss the therapist.” [Nancy]</li> <li>• “That [walking] was very challenging. Oh my God! Yeah. Yeah I could just walk around the food court. Even that was unbelievably challenging... but eventually by the time... it [the pandemic] came in 2020... I was actually able to walk the whole [mall] at least one, one time all the way from food court to the [specific] store [name] and back and [then] back.” [Dorothy]</li> <li>• “She [my wife] could see the improvements in myself. She couldn’t believe it... There was one night that I said ‘Well, I’m going to the bathroom, and I’m just going to walk there.’ We didn’t have a cane at the time, and we had like, an island that came over way to the kitchen. I got up from the wheelchair and I took a couple steps with holding onto a chair. And then a couple more steps. And I was on the island holding onto the island, went around the island [a] couple of steps further, and once I got on the other side of the island and I could hold onto the stove, and next thing you know, I’m in the washroom! And so the next day, we went over to pick up a quad cane and well, that was super.” [Eli]</li> <li>• “Look at me now. It [the improvement] is amazing.” [Eli]</li> </ul>

---

## **Chapter Four: Discussion**

The purpose of this constructivist qualitative study was to explore the stroke-related experiences including exercise and rehabilitation, of those living in Thunder Bay. The findings revealed six themes and eight subthemes that were divided into two categories based on the participant's actual stroke experience and rehabilitation journey. The themes and subthemes included meaningful insights into getting help after a stroke, the physical and mental effects the participants faced, losing rehabilitation services during the pandemic, the importance of social support, and taking pride in one's success stories. Findings are framed below within the two categories that emerged from the analysis. This included information regarding one main qualifier for this study; the Northwestern Ontario population, in addition to discussing the findings related to the three basic psychological needs; relatedness, competence, and autonomy. Through these findings, two main recommendations emerged with a focus on improving the experiences of those who have had a stroke in Thunder Bay which include: 1) increasing purposeful education to the general public about stroke; and 2) increasing access to rehabilitation during the chronic phase of a stroke.

### **Actual Stroke Experiences**

#### ***Physical and Mental Effects After Stroke***

The side effects that come as a result of a stroke are widely studied as they happen immediately (Katoozian et al., 2018; Ostwald et al., 2015; Purton et al., 2021). Much of the literature in this area focuses on the physical effects present at the hospital and how the effects change during and after rehabilitation (Grypdonck, 2008). For all the participants in the present study, they were all faced with different physical, mental, and emotional complications, which is common for this population (Northcott et al., 2015). Although the physical effects are well

documented (Grypdonck, 2008), there is limited research looking into if the physical effects from a stroke affect individuals mentally. This was a widely talked about topic through the interviews in the current study, as participants explained in great detail how the physical effects impacted their mental health and vice versa. One study conducted by Kitzmuller et al. (2013) similarly found that those who have had a stroke often live with an altered perception of self, due to their bodily changes. A second study (Silva et al., 2016), explored the perspectives of life after stroke through semi-structured interviews and found that physical restrictions caused emotional changes to one's self-esteem, ability to work, social, and financial life. These may be potential reasons the current participants felt these mental hardships; however, it was not discussed in enough detail to make causal determinations. Further study on the relationship between the mind and body is warranted, as it seemed that the mental effects from the stroke originated from their physical inabilities. By gaining a better understanding of the mind-body connection in relation to stroke rehabilitation, an easier transition for patients through their rehabilitation journey may be realized as it would be a holistic approach (Silva et al., 2016). Specifically, for those who have had a stroke, understanding that the effects are multifaceted is important in treating the individual's needs (Silva et al., 2016).

In addition to the emotional challenges that seemed to relate to the physical ramifications after stroke, there are also emotional hardships that occur independently for a variety of other reasons. Individuals can feel sadness, hopelessness, and become less interested in activities they once enjoyed (Silva et al., 2016). When an individual feels this way, it has been seen to slow the process of recovery both physically and mentally (Silva et al., 2016). Within the literature, feelings of negative emotions have been evaluated months after the stroke but not during the acute phase (Burvill et al., 2018). For the participants in this current study, they all felt negative

emotions, particularly during the acute phase of the stroke. Thus, it was evident that the beginning stage after the stroke was a challenging time for study participants: a finding which mirrored conclusions of Silva et al. (2016). For future stroke survivors, increased time and effort should be spent by healthcare workers with the patient to observe and understand any negative emotions felt during the acute phase (Silva et al., 2016). As stroke is a traumatic experience, having referrals available to help navigate the changes is warranted to help improve one's experience during the acute phase.

Along with the physical and mental hardships associated with stroke, there was also one particular experience where all participants in this current study felt negative emotions. This was when their driver's license was taken away during the acute phase. To date, most of the research regarding one's driver's license post-stroke revolves around reinstating (Akinwuntan et al., 2012; Motta et al., 2014). Although important from a procedural perspective, these studies are missing how the loss affects an individual during the acute phase of a stroke. One study that explored this concept was Liddle et al. (2012) who used semi-structured interviews to gain an understanding of the needs and experiences of those who ceased driving after stroke. Liddle et al. (2012) explained that participants felt like it was a sudden and intense experience accompanied by challenges such as needing to arrange for alternative transport, greater reliance on their carers, and needing more information about the process. These findings were more comprehensive than the current study; however, since there were no questions regarding one's driver's license in the current interview guide, it is evident that this was an important and memorable moment during their stroke experience. As this was a noteworthy moment for all participants, it suggests that attention should be paid by healthcare professionals with regards to providing more support and information on driving cessation (e.g., alternatives to driving and transportation; Liddle et al.,

2012). Since this process is out of the patient's control, giving them support is essential as these participants felt that it was a hard experience to undergo.

## **The Rehabilitation Journey**

### ***Stroke Rehabilitation in Northwestern Ontario***

One main qualifier for this current study was to explore the experiences of those who have had a stroke in Northwestern Ontario due to the limited research in this population. The studies that have been conducted have concluded that Northern Ontario cities are more susceptible to higher readmission rates for those with a heart attack or stroke (Donio et al., 2020), in addition to worse outcomes due to the lack of resources and services (Shurrab et al., 2017). This current study uncovered a few related findings which have been discussed below aimed to add to the limited existing literature regarding Northern Ontario stroke rehabilitation.

In this current study, all participants reported going through the typical after-stroke care that is common for this population. They were admitted to hospital, stayed for at least a few days, and were provided with in-patient rehabilitation services and formal rehabilitation programming, showcasing the consistent process Thunder Bay has for stroke patients. The participants expressed multiple times throughout the interviews however how they felt lost after their formal rehabilitation programming ended. All participants also explained how they had to make their own choices regarding next rehabilitation steps, and further find services themselves. In Ontario, there is limited research regarding community-based rehabilitation services for stroke patients and how this may affect them (Donnelly et al., 2021). The Canadian Institute for Health Information 2012 report suggests that the outpatient and community-based rehabilitation resources available across the country were not enough to meet the increasing demand at that time. The 2012 report authors believed this was due to cost-saving measures at the system level

(e.g., cutbacks) which resulted in fewer outpatient services than in the past. Although the report is dated, the findings are still evident 10 years later as the need for outpatient stroke rehabilitation is still an increasing need (Donnelly et al., 2021). The current study confirmed the ongoing need of outpatient rehabilitation services, specifically in Northwestern Ontario as the 2012 report did not define what areas of Ontario were being assessed. For future studies and reports, due to the differences in care between Northern and Southern Ontario (Donio et al., 2020; Shurrab et al., 2017), it may be warranted to explore these differences specifically regarding outpatient rehabilitation further, as it is evident that more resources are needed.

In a more recent study conducted by Donnelly et al. (2021), community stroke rehabilitation (i.e., home, outpatient, and virtual rehabilitation services) across Ontario were reviewed by collecting resources related to the current community stroke rehabilitation programs. It was deemed important as there is wide variability regarding funding models, the organizations that deliver the programs, and program evaluation (Donnelly et al., 2012). The results from this study concluded that community stroke rehabilitation had a positive impact on individual patient recovery through reviewing documents provided to this report from every province. Although it was a relatively small sample size (73 resources) in relation to the entire province of Ontario, Donnelly et al. (2021) used three resources to gain an understanding of Northwestern Ontario, whereas Southern Ontario regions had many more resources. This discrepancy highlights that the findings from the study may not be transferable to Northwestern Ontario and that future research may need to separate these regions of the province. When comparing Donnelly et al. (2012) to the current study, the findings are different. Some participants in the current study were not happy with their community or outpatient rehabilitation services because many were not offered it. It may be possible that there is no funding available to



further pursue maintenance programs after stroke (Donio et al., 2020), however, this current study highlights the need for long-term resources and services after all formal rehabilitation is complete in Northwestern Ontario. Since this current study only focused on participants from Northwestern Ontario (specifically Thunder Bay), it is not feasible to directly compare the experiences between those in Southern and Northern Ontario. Given the differences in access and resources that occur for the stroke population (Shurrab et al., 2017) it is possible that the experiences of these people would be different, however more data, both qualitative and quantitative in Southern Ontario and Northern Ontario, is needed to explore this.

### ***Losing Rehabilitation Services During the COVID-19 Pandemic***

Due to the recent COVID-19 pandemic, exploring related experiences was timely and warranted. One common idea expressed throughout the interviews was the hardships experienced when losing rehabilitation services. In this study, there were four participants who had their stroke either just before or during the pandemic. These participants were not offered rehabilitation services due to the lockdown and were expected to carry out rehabilitation on their own. The research regarding the COVID-19 pandemic and rehabilitation delays have not discussed those who have had delays in receiving care; instead, has only investigated hospital admission declines and the reduction in stroke care offered at these hospitals (Zhao et al., 2020). For the current study, for the participants who had a stroke during the pandemic, it is valuable seeing their perspective in which delays receiving rehabilitation services and being forced to find their own home programming affected them negatively. It was also of interest to note that all four of these individuals did partake in home exercises after in-patient care ended through their own volition; which is not typically common for someone who has not undergone rehabilitation (Mayo, 2016). A few reasons for this may have involved fear experienced after the stroke had

occurred (e.g., fear of the unknown); being active prior to the stroke and wanting to maintain that; and already having a rehabilitation team for other complications from which to draw (Wiley, 2020).

This study also added complementary points of view from participants who had their stroke before the pandemic. Regardless of stroke onset timing, all participants stated that they were affected by the lack of rehabilitation during the pandemic as they described needing to find rehabilitation on their own. This was detrimental to their care due to the increased stress in needing to find rehabilitation services. This perspective is valuable as it gives insight into the patient's point of views during a time that was unpredictable. The findings associated with the theme *losing rehabilitation during the COVID-19 pandemic* can be applied to other patients with chronic disease in different countries and cities as rehabilitation was taken away from all patients at some point during the pandemic (Torriani-Pasin et al., 2021). If a similar situation were to arise like the COVID-19 pandemic, it would be of importance to ensure other modes of rehabilitation were used for all patients and further check-ins with patient's were completed to ensure rehabilitation was being understood and completed. In addition to this, helping patients navigate this loss of rehabilitation and furthermore providing and encouraging other rehabilitation options (i.e., at home) would be of benefit to facilitate ongoing progress (Wiley, 2020).

### ***Supporting the Self-Determination Theory's Basic Psychological Needs After Stroke***

For individuals who have had a stroke, maintaining autonomous motivation (i.e., engaging in a behaviour because it is consistent with one's intrinsic goals; Hagger et al., 2014) is essential, especially in the domain of health and wellness (Eassey et al., 2020). Autonomous motivation is important because it allows individuals, specifically those undergoing a

challenging experience like chronic disease, a sense of choice and satisfaction; factors that will likely facilitate sustained behaviour (Hagger et al., 2014). This notion has been defined further through a sub-theory of self-determination theory which posits that human beings have three fundamental psychological needs that must be satisfied to optimize growth and human potential (Deci & Ryan, 1985; Ryan & Deci, 2000). These include relatedness, competence, and autonomy. Relatedness has been defined as feeling close to someone, some thing, and/or belonging to a social group (Deci & Ryan, 2012). The second basic psychological need, competence, involves gaining a sense of mastery over a task and learning different skills (Deci & Ryan, 2012). Lastly, autonomy can be defined as having a choice and willingly engaging in a behaviour of one's own volition (Deci & Ryan, 2012). In relation to stroke, understanding how these three basic psychological needs shape one's experience is limitedly researched (Lau et al., 2022). Lau et al. (2022) concluded that satisfaction of the three psychological needs is associated with motivation for daily physical activity participation and may foster autonomous motivation in stroke survivors.

For relatedness, all participants in this current study discussed having high levels of positive support in the form of feeling close to others. The participants described how having these connections throughout their stroke experience and rehabilitation journey was a main reason for their rehabilitative success. In the literature, having high levels of support after stroke has been associated with a greater rate of recovery along with faster and more extensive recovery of one's functional status (Barker & Brauer, 2009; Glass et al., 1993). Evans et al. (1991) also concluded that households with only satisfactory homecare situations (i.e., poor family dynamics or limited positive support), resulted in more depression and family dysfunction. For the participants in this research study, all reported great support at home, except for one individual

who instead, found high levels of support through healthcare practitioners and friends. Relatedness also plays an important role when internalizing activities that are not inherently interesting to that person (Lau et al., 2022). These findings may be in line with this current study's sample as all participants shared that they learned to enjoy exercise and rehabilitation due, in large part, to the social supports they found. This in turn may have influenced the participant's recovery process positively. While the study design precludes any cause-and-effect conclusions from being made, future investigation with a specific focus on mechanisms for promoting relatedness in this population is needed (Lau et al., 2022).

When someone experiences competence, they are more likely to take action to further achieve their goals, as they are confident in their abilities (Deci & Ryan, 2000). For the participants in this study, competence seemed evident as individual success stories were shared. When experiencing something as significant and lifechanging as a stroke, recognizing and talking about one's successes is crucial, especially from a patient's point of view (Horne et al., 2014). In the literature, the idea of success is explained as follows: success is built on success, and that confidence comes from taking ownership and pride in one's own successes (Wagner & McMahon, 2004). Although this is a broad description, it does hold merit within and relevance to the present research study. Many of the participants described an instance where they had experienced success and felt pride in relation to their rehabilitation journey. Because participants in this sample appeared to be motivated and driven during their rehabilitation and felt comfortable sharing their successes with the interviewer, it would appear that they had built a sense of confidence (Wagner & McMahon, 2004). This mirrors a study by Horne et al. (2014), where participants were asked about their feelings of confidence, and they reported not feeling competent in familiar activities (i.e., walking the dog) due to the loss of confidence in

themselves. It would be beneficial for other stroke survivors who have yet to achieve this level of confidence to continue working towards this idea of competence; however, it may come with time, experience, and one's rehabilitation journey (Horne et al., 2014). Through one's rehabilitation journey, confidence can be instilled through the healthcare workers and family members the individual surrounds themselves with (Lau et al., 2022). From here, stroke survivors will begin to feel confident in the things they are learning and begin to see changes, thus increasing their levels of competence (Lau et al., 2022).

The final term basic psychological need, autonomy, was apparent in this current participant sample given they were all willingly engaging in exercise towards the end of their formal rehabilitation period. Participants shared that they wanted to do everything they could to mitigate the negative effects of the stroke, enjoyed the activity, and wanted to keep healthy. Throughout the months of formal rehabilitation, participants were able to learn enough about exercise and rehabilitation, and further utilize their previous knowledge about exercise and rehabilitation to be competent in their abilities and further become autonomous in their choices afterwards. These choices for every participant involved completing rehabilitation and exercise on their own. It is a surprising find, as in the literature, fostering motivation is noted as the most difficult aspect of work that therapeutic professionals do (Maclean, 2000). Lau et al. (2014) also concluded that out of the three basic psychological needs, autonomy was the main predictor of autonomous motivation in a population of 40 community-dwelling stroke survivors. This was because with autonomy, individuals have control over choosing activities they enjoy and value, thus resulting in the individual continuing the activity (Lau et al., 2022). As most of the sample had their stroke a number of years ago, it may be the case that heightened levels of autonomy were attributed to their experiences over the years and likely they had to work towards this

(Horne et al., 2014). Further research is warranted to explore the relationship between autonomy and rehabilitation to help other stroke survivors reach high levels of autonomy and ultimately increase their well-being and quality of life (Lau et al., 2022).

Based on the findings of the present study, it is likely that all participants were showing that they endorsed each basic psychological need to some degree; however, further testing is warranted to explore this further. As this endorsement is not typical of most individuals who have had a stroke (Mayo, 2016), it highlights the importance of addressing these needs during the recovery period. Thus, it is important to continue researching those people in both the acute and chronic phase of a stroke in relation to the three basic psychological needs to further understand how these concepts relate to one another. Further discussion via interviews would be beneficial as this current study gained a better perspective on the three needs, however greater emphasis on each psychological need would be warranted in the interview guide.

### **Future Implications for Stakeholder Groups**

#### ***Purposeful Education About Stroke Signs and Symptoms Needed for the General Public***

Two recommendations emerged from the study interviews to showcase to future stakeholders (Thunder Bay Regional Health Sciences Centre and St. Joseph's Care Group). The first recommendation is to include purposeful education to the general public about stroke to improve knowledge of warning signs and time of response after a stroke occurs. This may be multi-tiered approach as there are many parts to think about. This may include policy makers, the government, health promoters, and educators to name some. Due to the nature of the interview guide for this study, participants were able to discuss experiences from when the stroke occurred, in addition to before, during, and after rehabilitation. As a result of the different timelines, an overwhelming theme across the first category, on the *actual stroke experience*, was the limited

knowledge participants had about stroke during the acute phase. It is important to learn about the process before going to the hospital as studies have concluded that the public's knowledge regarding what a stroke is, the symptoms of a stroke, and the proper reaction to a stroke is quite deficient across the world (Hickey et al., 2018; Krishnamurthi et al., 2020). Indeed, Fussman et al. (2010) completed telephone surveys with 4841 adults to examine the association between warning sign knowledge of a stroke and calling emergency services. It was concluded that 27% of participants had adequate knowledge of warning signs and 14% reported they would call 911 based on three stroke-related scenarios (Fussman et al., 2010). The results of Fussman et al. (2010), although quantitative in nature, do show similar findings to one theme of this current research study; *getting help is complex*.

Over the years, the same reoccurring problem has happened across the world in urban and remote cities where the public's awareness of stroke risks, signs, and symptoms is concerningly low (Fussman et al., 2010; Hickey et al., 2018; Krishnamurthi et al., 2020). Different campaigns (i.e., Face, Arm, Speech, and Time; FAST campaign), in addition to pamphlets and conferences have been used to try to raise awareness of the signs and symptoms associated with stroke (Hickey et al., 2018). Although these types of educational methods are important, with no increases in knowledge retention, it is evident that something further needs to be done. For some individuals who are having a stroke, the reasoning for delayed admission to hospital can be related to the individual's shame, uncertainty regarding the stroke, and being in denial or shock (Alegiani et al., 2019). It is possible for these to be reasons why the current study's sample did not receive care right away, but it is not known. As stroke admission rates continue to rise, future research is warranted to investigate further into why individuals delay their admission as it is important for treatment to occur right away to mitigate any further affects

(Hickey et al., 2018). It is also of importance to improve the educational system to the general public regarding stroke to make it more individualized and eye-opening to the public, thus being more purposeful (Alegiani et al., 2019). Again, this may be a multi-tiered approach as it would need to include policy makers, the government, health promoters, and educators. On an individual level, this could include personalized counselling for those with known risk factors or for all individuals as they age through their general healthcare practitioner (Alegiani et al., 2019).

***“You shouldn’t [need to find your own rehabilitation because] you’re sick”: Help Make Access to Rehabilitation Easier in Chronic Stroke Phase***

Through the findings gleaned through the interviews, it is evident that the pathway through stroke rehabilitation is quite complex and individualized. Within the literature, there is limited research regarding the personal experiences of these individuals through a qualitative lens (Brajkovic et al., 2009; Chen et al., 2011; Michael et al., 2015; Nicholson et al., 2017; Rimmer et al., 2008), specifically for individuals living in Northwestern Ontario (Shurrab et al., 2017) and during a worldwide pandemic. The rehabilitation journey for someone who has had a stroke often includes many options depending on the individual’s needs. For the participants in this study, they all took relatively similar paths through stroke rehabilitation which may be due to their location of living. This was an important piece of this study as it shows that the services available in Thunder Bay have a consistent plan for their patients when being discharged from the hospital to their next formal rehabilitation steps. In smaller cities like Thunder Bay, there can be fewer options for individuals which results in them undergoing similar care plans (Winn et al., 2014). Another related commonality seen across the second distinct category, *the rehabilitation journey*, was the notion of needing to find rehabilitation on their own at some point during their experience. For these participants, this was felt during their rehabilitation when having other



complications not related to stroke, and then finally when they finished their formal stroke rehabilitation.

In the literature, it has been seen that a stroke is often the beginning of other hardships in relation to physical impairment or subsequent disability (Chohan et al., 2019). There is often a variety of lesser-known medical, musculoskeletal, and psychosocial difficulties (Chohan et al., 2019). It is recommended by Chohan et al. (2019) for the primary care physician to aid in reducing the risk and manage complications of these further injuries or diseases. For other chronic diseases such as heart attacks, research has focused on patients who may be at risk for other complications after completing cardiac rehabilitation and further allocating them to a program or healthcare practitioner matched to their risk strata (Grace et al., 2016). This would be beneficial for stroke survivors as even if they were to not use the resource right away, at least it is available for if or when the time may come.

For the participants in this study, it did not seem to be a problem receiving care during the acute phase of their stroke; however, all participants struggled to find rehabilitation after their formal rehabilitation programming was finished, highlighting this idea of forced independence. In the literature, it is unknown if patients undergoing stroke or other chronic diseases feel responsible for finding future rehabilitation and programming after their formal acute rehabilitation has finished. It does allude to the fact that Southern Ontario has greater access to healthcare systems, more opportunities, and more funding for patients (Shurrab et al., 2017). Teasell et al. (2014) completed a systematic review knowing that although stroke survivor recovery may plateau within 3-6 months of their stroke, the evidence for rehabilitation during the chronic stage is limited. It was concluded that there is robust evidence to ensure stroke rehabilitation interventions are in place during the chronic stroke phase, however, concluded that

limited resources are available for those with chronic stroke. This is evident through the current study's findings as participants said they were only allowed to do a certain number of weeks in formal rehabilitation until they had to make decisions regarding next steps on their own. Due to this, it could be concluded that since Thunder Bay stroke-related services have limited chronic stroke rehabilitation resources, this theme of *forced independence can lead to next rehabilitation steps* may be a concept that is only applicable to smaller cities and communities. It may also be possible that because the programs are only a certain number of weeks in duration, may be hindering the individual's opportunity to be more successful and thus need longer programming for these individuals. For other chronic diseases in Thunder Bay such as cancer, there are exercise and support groups made available to all patients and further are provided maintenance programs that the individual may partake in for the rest of their life (Morris et al., 2021). This concept could be transferred to similar groups such as stroke as it is evident long-term stroke rehabilitation is needed (Teasell et al., 2014).

From a community perspective, the findings from this study can be shared with local stakeholders like Thunder Bay Regional Health Sciences Center and St. Joseph's Care Group. Specifically, two findings in particular would be beneficial to address: 1) increasing purposeful education to the general public about stroke, and 2) help make access to rehabilitation during the chronic phase easier. By sharing the suggestions with these facilities, it will allow awareness to be brought to the findings that may need improvements. It is also valuable for these facilities to understand the strategies that are being done well and that participants enjoyed. On a broader level, the findings from this study can also be transferred into like communities or cities comparable to Thunder Bay as the findings may be similar for those with stroke or even another chronic disease.

## Study Strengths

As there has been limited studies looking into the rehabilitation and exercise experiences in Northwestern Ontario of those who have had a stroke through a qualitative lens, the findings from this study can be a reference for future studies in similar contexts. Although this study had unique characteristics such as exploring the COVID-19 rehabilitative experiences and limiting the participants to those only in Thunder Bay, Ontario, this still allowed for the emergence of unique findings. In addition, another strength of this study was that the themes generated from the data were dominant throughout the majority of the interviews, showing that data saturation had been obtained for this population. In addition, due to little research being conducted regarding the COVID-19 pandemic in relation to stroke rehabilitation, this study added a missing perspective for this specific population.

Another strength for this study was the characteristics of this population's sample, although it was heterogenous regarding the demographic questions: age, type of stroke, and time since stroke. As all participants in this study did partake in exercise and rehabilitation, the perspectives regarding these constructs are strong due to their involvement and expertise. This allows this study to showcase a unique population, as it is often uncommon to meet a keen and eager group to participate in exercise and rehabilitation regularly after stroke.

Prior to this study, in the summer of 2021, a pilot study was completed for this project which enhanced the reliability of the interview guide and interviewer skills (student researcher). All recommendations were made from that study which included making sure all participants completely understood the questions, changing the interview guide to ensure there were only open-ended questions, and adding probing and guiding questions into the interview guide. All of

these points were addressed which allowed the interviewer to gather more in-depth responses from all of the participants to create rich data.

### **Study Limitations**

One limitation for this study may be the mean age ( $M = 69.2$ ) of the participants. In this study, 50% of the participants had their stroke when they were in their 60s, with 30% of participants being in their 50s. It may be possible that these individuals were generally more active and had fewer co-morbidities at the time of their stroke, due to their age. If this is true, it may mean that these participants had more motivation to partake in exercise and rehabilitation after their stroke and further continuing that in their everyday life.

Although gender was noted as a demographic question throughout the interview, no main findings were revealed within the data in relation to gender. As the purpose of this study was to explore the experiences of all stroke survivors, future research is warranted to investigate the similarities and differences between genders to be able to conclude further findings. All participants in this study, despite their gender, shared similar stories and experiences.

As mentioned before, the participants in this current study were all keen to participate in exercise and participate in this research study, and although may have been a strength for this study, can also be seen as a limitation. This is because it may not be an accurate representation of all stroke survivors in Thunder Bay, as it would be more difficult to discuss with individuals with severe stroke effects to understand what their experiences were like. Despite this, it is a good representation of stroke survivors who have limited long-term effects after stroke. As this study occurred during the midst of the COVID-19 pandemic, the need for interviews to occur over the telephone or Wi-Fi compatible device was necessary. While an efficient strategy which enables extensive reach and ease for participants, it would also be recommended, particularly for this

population, to conduct the interviews in person. A few participants asked if the interviews could be completed in person but with the COVID-19 restrictions, this was not possible. It would be beneficial for the participants to meet the interviewer in-person which may have further warranted the comfort of the participants. This may have been a limitation for this study as it may have been difficult for some individuals to feel comfortable opening up with the interviewer although participants understood it was in their best interest. Although the pandemic restrictions only allowed for virtual interviews and was noted as a limitation, it also demonstrates how research methodology (i.e., telephone interviews) with stroke survivors is feasible and can be used in the future by other researchers with similar populations.

## Chapter Five: Conclusion

As the population continues to age, along with the prevalence of stroke increasing, exploring the experiences of those with such a prevalent disease is timely and warranted. In smaller cities and communities such as Thunder Bay, where there are fewer resources and services to aid with stroke rehabilitation compared to large municipalities, it is important to understand how and if this affects these individuals. As much of the research conducted with this population does not involve speaking directly with the survivors, this study was able to give unique insights into the stroke experiences and rehabilitative journeys of those living in Thunder Bay in relation to the overall quality of their care and further make recommendations. This study found six themes and eight subthemes which ranged from getting help after a stroke, the physical and mental effects the participants faced, losing rehabilitation during the pandemic, social support, one's success stories, and furthermore taking pride in those stories. The findings confirmed the need for community-based rehabilitation services in Thunder Bay extending beyond the acute phase and further discussed the study's sample in regards to the having high levels of the three basic psychological needs. From these findings, two recommendations were derived that will be presented to regional stakeholders which included needing to: 1) increase purposeful education to the general public about stroke through individual risk counselling, and 2) make access to rehabilitation easier during the chronic stroke phase by following methods completed by other similar groups, such as cancer survivors, in Thunder Bay. The findings from this study are helpful in raising awareness of the experiences of stroke survivors living in Thunder Bay. This study allowed participant's voices to be recognized regarding the positive and negative experiences related to their care and share new perspectives related to rehabilitation during the COVID-19 pandemic.

## References

- Akinwuntan, E. A., Wachtel, J., & Rosen, N. P. (2012). Driving simulation for evaluation and rehabilitation of driving after stroke. *Journal of Stroke and Cerebrovascular Diseases*, *21*(6), 478-486. doi: 10.1016/j.jstrokecerebrovasdis.2010.12.001
- Alberts, L. M. (2012). Improving public education about stroke. *ANNALS of the New York Academy of Sciences*, *1268*(1), 45-50. doi: 10.1111/j.1749-6632.2012.06722.x
- Alegiani, C. A., Albrecht, S., Rahn, C.A., Kopke, S., Thomalla, G. & Heesen, C. (2019). Reasons for delayed admission after stroke: Results of a qualitative and quantitative survey. *Patient Preference and Adherence*, *13*(1), 739-747. doi: 10.2147/PPA.S193376
- Anderson, C., Rubenach, S., Mhurchu, N. C., Clark, M., Spencer, C., & Winsor, A. (2000). Home or hospital for stroke rehabilitation? Results of a randomized controlled trial: Health outcomes at six months. *Stroke*, *31*(5), 1024-1031. doi: 10.1161/01.STR.31.5.1024
- Andres, K., Arthur, G., Cameron, J., Field, T., DeVeber, G., Finestone, H., Ganann, R., Gierman, N., Green, T., & Harrison, E. (2017). *Different strokes: Recovery triumphs and challenges at any age*. Heart and Stroke Foundation of Canada.
- Barker, N. R., & Brauer, G. S. (2009). Upper limb recovery after stroke: The stroke survivors' perspective. *Disability and Rehabilitation*, *20*(1), 1213-1223. doi: 10.1080/09638280500075717
- Beaulieu, S. M., & Kirker, L. J. (2021). *The continued evolution of Fort William and Port Arthur into the city of Thunder Bay, Ontario, Canada*. Routledge.

- Bethoux, F., Calmels, P., & Gautheron, V. (1999) Changes in the quality of life of hemiplegic stroke patients with time. *American Journal of Physical Medicine and Rehabilitation*, 78(1), 19-23.
- Billinger, A. S., Arena, S., Bernhardt, J., Eng, J. J., Franklin, A. B., Johnson, M. C., MacKay-Lyons, M., Macko, F. R., Mead, E. G., Roth, J. E., Shaughnessy, M., & Tang, A. (2014). Physical activity and exercise recommendations for stroke survivors. *Stroke*, 45(8), 2532-2553. doi: 10.1161/STR.0000000000000022
- Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Innovative Methods*, 26(13), 1802-1811. doi: 10.1177/1049732316654870
- Bolognini, N., Russo, C., & Edwards, J. D. (2016). The sensory side of post-stroke motor rehabilitation. *Restorative Neurology and Neuroscience*, 34(4), 571-586. doi:10.3233/RNN-150606
- Brajkovic, L., Godan, A., Godan, L. (2009). Quality of life after stroke in old age: Comparison of persons living in nursing homes and those living in their own home. *Croatian Medical Journal*, 50(2), 182-188. doi: 19.3325/cmj.2009.50.182
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101. doi: 10.1191/1478088706qp063oa
- Burvill, W. P., Johnson, A. G., Jamrozik, D. K., Anderson, S. C., Stewart-Wynne, G. E., & Chakera, M. T. (2018). Prevalence of depression after stroke: The perth community stroke study. *The British Journal of Psychiatry*, 166(3).



- Cameron, V. (2013). Best practices for stroke patient and family education in the acute care setting: A literature review. *Medsurg Nursing Journal*, 22(1), 51-64.
- Canadian Institute for Health Information. (2012). *Pathways of Care for People With Stroke in Ontario*.
- Chaiyawat, P., & Kulkantrakorn, K. (2012). Effectiveness of home rehabilitation program for ischemic stroke upon disability and quality of life: A randomized controlled trial. *Clinical Neurology and Neurosurgery*, 114(7), 866-870. doi: 10.1016/j.clineuro.2012.01.018
- Chen, M., & Rimmer, H. J. (2011). Effects of exercise on quality of life in stroke survivors. *Stroke*, 42(3), 832-837. doi: 10.1161/STROKEAHA.110.607747
- Chohan, A. S., Venkatesh, K. P., & How, H. C. (2019). Long-term complications of stroke and secondary prevention: An overview for primary care physicians. *Singapore Medical Journal*, 60(12), 616-620. doi: 10.11622/smedj.2019158
- Connelly, M. L. (2016). Trustworthiness in qualitative research. *Medsurg Nursing*, 25(6), 425-436.
- Creswell, W. J. (2014). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. SAGE Publications Incorporation.
- Deci, L. E., & Ryan, M. R. (1985). *Intrinsic motivation and self-determination in human behaviour*. New York, NY: Plenum.
- Donio, J. P., Freitas, C., Austin, C. P., Ross, J. H., Abdel-Qadir, M. H., Wijeyesundera, C. H., Tu, K., Cram, P., Liu, P., Abrams, H., Udell, A. J., Mak, S., Farkouh, E. M., Tu, V. J., Wang,

- X., Tobe, W. S., & Lee, S. D. (2019). Comparison of readmission and death among patients with cardiac disease in northern vs southern Ontario. *Canadian Journal of Cardiology*, 35(3), 341-351. doi: 10.1016/j.cjca.2019.01.004
- Donnelly, B., Huffman, S., Angrand, L., Williams, S. (2021). *Establishing a foundation for sustainable community stroke rehabilitation evaluation in Ontario: A review of current state and future recommendations*. Ontario Regional Stroke Network.  
www.strokenetworkseo.ca
- Eassey, D., Reddel, K. H., Ryan, K., & Smith, L. (2020). "It is like learning how to live all over again." A systematic review of people's experiences of living with a chronic illness from a self-determination theory perspective. *Health Psychology and Behavioural Medicine*, 8(1), 270-291. doi: 10.1080/21642850.2020.1794879
- Elliott, C. (1997). Caring about risks: Are severely depressed patients competent to consent to research. *Archives of General Psychiatry*, 54(2), 113-116. doi: 10.1001/archpsyc.1997.01830140021003
- Elo, S., Kaariainen, M., Kanste, O., Polkki, T., Utriainen, K., & Kyngas, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE OPEN*, 1-10. doi: 10.1177/2158244014522633
- Eng, J. J., & Reime, B. (2015). Exercise for depressive symptoms in stroke patients: A systematic review and meta-analysis. *Clinical Rehabilitation*, 28(8), 731-739. doi: 10.1177/0269215514523631
- Eng, W. X., Brauer, G. S., Kuys, S. S., Lord, M., & Hayward, S. K. (2014). Factors affecting the ability of the stroke survivor to drive their own recovery outside of therapy during

inpatient stroke rehabilitation. *Stroke Research and Treatment*, 20(1), 1-8. doi:  
10.1155/2014/626538

Evans, L. R., Bishop, S. D., & Haselkorn, K. J. (1991). Factors predicting satisfactory home care after stroke. *Physical Medicine and Rehabilitation*, 72(2), 144-147. doi:  
10.5555/uri:pii:000399939190123Z

Fahey, D. T., Insel, M. P., Roth, T. W., & Wong, E. I. (2016). *Fit & well: Core concepts and labs in physical fitness and wellness*. McGraw-Hill Ryerson Limited.

Frizzell, P. J. (2005). Acute stroke: Pathophysiology, diagnosis, and treatment. *Neurological Nursing*, 16(4), 421-440.

Fusch, I. P., & Lawrence, R. N. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20(9), 1408-1416.

Fussman, C., Rafferty, P. A., Lyon-Callo, S., Morgenstern, B. L., & Reeves, J. M. (2010). Lack of association between stroke symptom knowledge and intent to call 911. *Stroke*, 41(7), 1501-1507. doi: 10.1161/STROKEAHA.110.578195

Gaetano, A. (2016). Relationship between physical inactivity and effects on individual health status. *Journal of Physical Education and Sport*, 16(2), 1069-1074. doi:  
10.7752/jpes.2016.s2170

Glass, A. T., Matchar, B. D., Belyea, M., & Feussner, R. J. (1993). Impact of social support on outcome in first stroke. *Stroke*, 24(1), 64-70. doi: 10.1161/01.STR.24.1.64

Gordon, F. N., Gulanick, M., Costa, F., Fletcher, G., Franklin, A. B., Rother, J. E., & Shepard, T. (2000). Physical activity and exercise recommendations for stroke survivors. *Stroke*

- , 35(5), 1230-1240. doi: 10.1161/01.STR.0000127303.19261.19
- Grace, L. S., Turk-Adawi, K., Araujo, C., & Alter, A. D. (2016). Ensuring cardiac rehabilitation access for the majority of those in need: A call to action for Canada. *Canadian Journal of Cardiology*, 32(10), 358-364. doi: 10.1016/j.cjca.2016.07.001
- Gresham, E. G., Stasibm B. W., & Duncan, W. P. (2004). *Post-stroke rehabilitation*. DIANE Publishing.
- Grypdonck, M. (2008). Being a stroke patient: A review of the literature. *Journal of Advanced Nursing*, 26(3), 580-588. doi:10.1046/j.1365-2648.1997.t01-19-00999.x
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82. doi: 10.1177/1525822X05279903
- Hagger, S. M., Hardcastle, J. S., Chater, A., Mallett, C., Pal, S., & Chatzisarantis, L. N. (2014). Autonomous and controlled motivational regulations for multiple health-related behaviours: Between-and-within-participants analyses. *Health Psychology and Behavioural Medicine*, 2(1), 565-601. doi: 10.1080/21642850.2014.912945
- Hartman-Maeir, A., Soroker, N., Ring, H., Avni, N., & Katz, N. (2009). Activities, participation and satisfaction one-year post stroke. *Disability and Rehabilitation*, 29(7), 559-566. doi: 10.1080/09638280600924996
- Hickey, A., Mellon, L., Williams, D., Shelley, E., & Conroy, M. R. (2018). Does stroke health promotion increase awareness of appropriate behavioural response? Impact of the face, arm, speech and time (FAST) campaign on population knowledge of stroke risk factors,

- warning signs and emergency response. *European Stroke Journal*, 3(2). doi: 10.1177/2396987317753453
- Holland, A. L. (2002). Self-determination and self-advocacy: New concepts for aphasic individuals and their partners. *Neurobehavior of Language and Cognition*, 265(1), 109-116. doi: 10.1007/0-306-46898-0\_7
- Horne, J., Lincoln, B. N., Preston, J., & Logan, P. (2014). What does confidence mean to people who have had a stroke? A qualitative interview study. *Clinical Rehabilitation*, 1-11. doi: 10.1177/0269215514534086
- Jafar, N. A. (2018). What is positionality and should it be expressed in quantitative studies. *Emergency Medicine Journal*, 35(5). doi: 10.1136/emmermed-2017-207158
- Kapral, K. M., Hall, R., Gozgyra, P., Yu, X. A., Jin, Y. A., Martin, C., Silver, L. F., Swartz, H. R., Manuel, G. D., Fang, J., Porter, J., Koifman, J., & Austin, C. P. (2020). Geographic access to stroke care services in rural communities in Ontario, Canada. *Canadian Journal of Neurological Sciences*, 47(3), 301-308. doi: 10.1017/cjn.2020.9
- Katoozian, L., Tahan, N., Zoghi, M., & Bakhshayesh, B. (2018). The onset and frequency of spasticity after first ever stroke. *Journal of the National Medical Association*, 110(6), 547-552. doi: 10.1016/j.jnma.2018.01.008
- Kitzmuller, G., Haggstrom, T., & Asplund, K. (2013). Living an unfamiliar body: The significance of the long-term influence of bodily changes on the perception of self after stroke. *Medicine, Health Care and Philosophy*, 16(1), 19-29. doi: 10.1007/s11019-012-9403-y

- Koehn, S., & Amirabdollahian, F. (2021). Reliability, validity, and gender invariance of the exercise benefits/barriers scale: An emerging evidence for a more concise research tool. *International Journal of Environmental Research and Public Health*, 18(3516). doi: 10.3390/ijerph18073516
- Kowalski, K., McHugh, T., Sabiston, C., Ferguson, L. (2018). *Research Methods in Kinesiology*. Oxford University Press.
- Krishnamurthi, V. R., Barker-Collo, S., Barber, A. P., Tippet, J. L., Dalrymple-Alford, C. J., Tunnage, B., Mahon, S., Parmar, G. P., Moylan, M., & Feigin, L. V. (2020). Community knowledge and awareness of stroke in New Zealand. *Journal of Stroke and Cerebrovascular Diseases*, 29(3). doi: 10.1016/j.jstrokecerebrovasdis.2019.104589
- Kunkel, D., Fitton, C., Burnett, M., & Ashburn, A. (2014). Physical inactivity post-stroke: A 3-year longitudinal study. *Disability and Rehabilitation*, 37(4), 304-310. doi:10.3109/09638288.2014.918109
- Kyngas H., & Kaakinen, P. (2019). Deductive content analysis. *The Application of Content Analysis in Nursing Science Research*, 1, 23-30. doi: 10.1007/978-3-030-30199-6\_3
- Lau, C. S., Connor, T. L., & Baum, M. C. (2022). Associations between basic psychological need satisfaction and motivation underpinning daily activity participation among community-dwelling stroke survivors: An ecological momentary assessment study. *Archives of Physical Medicine and Rehabilitation*, 1-32. doi: 10.1016/j.apmr.2022.07.011
- Lawrence, M., Kerr, S., Watson, H., Paton, G., & Ellis, G. (2010). An exploration of lifestyle beliefs and lifestyle behaviour following stroke: Findings from a focus group study of

- patients and family members. *BMC Family Practice*, *11*(97). doi: 10.1186/1471-229611-97
- Lee, N., & Klarner, T. (2021). Exploring exercise and rehabilitation in stroke recovery through the lived experience: A pilot study.
- Legg, L., Leonardi-Bee, J., Corr, S., Edmans, J., Jongbleod, L., Sackley, C., Walker, M., & Langhorne, P. (2007). Occupational therapy for patients with problems in personal activities of daily living after stroke: Systematic review of randomized trials. *The British Medical Journal*, *335*. doi: 10.1136/bmj.39343.466863.55
- Liddle, J., Turpin, M., McKenna, K., Kubus, T., Lambley, S., & McCaffrey, K. (2012). The experiences and needs of people who cease driving after stroke. *Brainin Impairment*, *10*(3), 271-281. doi: 10.1375/brim.10.3.271
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- Lovell, P. G., Ansari, E. W., & Parker, K. J. (2010). Perceived exercise benefits and barriers of non-exercising female university students in the United Kingdom. *International Journal of Environmental Research*, *7*(1), 784-798. doi: 10.3390/ijerph7030784
- Luker, J., Lynch, E., Bernhardsson, S., Bennett, L., & Bernhardt, J. (2015). Stroke survivors' experiences of physical rehabilitation: A systematic review of qualitative studies. *Archives of Physical Medicine and Rehabilitation*, *96*(9), 1698-1708. doi: 10.1016/j.apmr.2015.03.017
- Maclean, N. (2000). A critical review of the concept of patient motivation in the literature on physical rehabilitation. *Social Science and Medicine*, *50*(1). 495-506.

- Maguire, M., & Delahunt, B. (2017) Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *All Ireland Journal of Teaching and Learning in Higher Education*, 8(3).
- Mayo, E. N. (2016). Stroke rehabilitation at home: Lessons learned and ways forward. *Stroke*, 47(6), 1685-1691. doi: 10.1161/STROKEAHA.116.011309
- Mercier, L., Audet, T., Hebert, R., Rochette, A., & Dubois, M. (2001). Impact of motor, cognitive, and perceptual disorders on ability to perform activities of daily living after stroke. *Stroke*, 32(11), 2602-2608. doi: 10.1161/hs1101.098154
- Merriam, S. B., & Tesdell, E. J. (2015). Qualitative research: A guide to design and implementation. Retrieved from <https://ebookcentral.proquest.com>
- Michael, K., Goldberg, P. A., Treuth, S. M., Beans, J., Normandt, P., & Macko, F. R. (2015). Progressive adaptive physical activity in stroke improves balance, gait, and fitness: Preliminary results. *Stroke Rehabilitation*, 16(2), 133-139. doi: 10.1310/tsr1602-133
- Morris, L. S., Newhouse, I., Larocque, T., Gillis, K., Smith, L., & Nisbet, K. E. (2021). Becoming one with nature: A nature intervention for individuals living with cancer participants in a ten-week group exercise and wellness program. *International Journal of Exercise Science*, 14(3), 498-518.
- Motta, K., Lee, H., & Falkmer, T. (2014). Post-stroke driving: Examining the effect of executive dysfunction. *Journal of Safety Research*, 49(1), 33-38. doi: 10.1016/j.jsr.2014.02.005
- Murali, V., & Hemachandra, R. P. (2016). Stroke, vascular dementia, and Alzheimer's disease: Molecular links. *Journal of Alzheimer's Disease*, 54(2), 427-443. doi: 10.3233/JAD-160527



- Nicholson, L. S., Donaghy, M., Johnston, M., Sniehotta, F. F., Van Wijck, F., Johnston, D., Greig, C., McMurdo, T. M., & Mead, G. (2013). A qualitative theory guided analysis of stroke survivors' perceived barriers and facilitators to physical activity. *Disability and Rehabilitation, 36*(22), 1857-1868. doi: 10.3109/09638288.2013.874506
- Nicholson, L. S., Greig, A. C., Sniehotta, F. F., Johnston, M., Lewis, J. S., McMurdo, T. M., Johnston, D., Scopes, J., & Mead, E. G. (2017). Quantitative data analysis of perceived barriers and motivators to physical activity in stroke survivors. *Journal of the Royal College of Physicians of Edinburgh, 47*(3), 231-236. doi: 10.4997/JRCPE.2017.302
- Nicholson, S., Sniehotta, F. F., Van Wijck, F., Greig, A. C., Johnston, M., McMurdo, T. M., Dennis, M., & Mead, E. G. (2012). A systematic review of perceived barriers and motivators to physical activity after stroke. *International Journal of Stroke, 8*(5), 357-364. doi: 10.1111/j.1747-4949.2012.00880.x
- Northcott, S., Moss, B., Harrison, K., & Hilari, K. (2015). A systematic review of the impact of stroke on social support and social networks: Associated factors and patterns of change. *Clinical Rehabilitation, 30*(8). doi: 10.1177/02692155155602136
- O'Reilly, M., & Parker, N. (2012). Unsatisfactory saturation: A critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research, 13*(1), 190-197. doi: 10.1177/1468794112446106
- Ostwald, K. S., Bernal, P. M., Cron, G. S., & Godwin, M. K. (2015). Stress experienced by stroke survivors and spousal caregivers during the first year after discharge from inpatient rehabilitation. *Stroke Rehabilitation, 16*(2), 93-104. doi: 10.1310/tsr1602-93
- Pacheco, D. B., Caetano, C. L., Samora, A. G., Sant'Ana, R., Teixeira-Salmela, F. L., & Scianni, A. A. (2019). Perceived barriers to exercise reported by individuals with stroke, who are

- able to walk in the community. *Disability and Rehabilitation*, 43(3), 331-337. doi: 10.1080/09638288.2019.1624396
- Purton, J., Sim, J., & Hunter, M. S. (2021). The experience of upper-limb dysfunction after stroke: A phenomenological study. *Disability and Rehabilitation*, 43(23), 3377-3386. doi: 10.1080/09638288.2020.1743775
- Rego, D. M. (2021). *The importance of explaining our lived experience*. <https://nami.org>
- Rimmer, H. J., Rubin, S. S., & Braddock, D. (2000). Barriers to exercise in african American women with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 81(2), 182-188. doi: 10.1016/s0003-9993(00)9013
- Rimmer, H. J., Wang, E., & Smith, D. (2008). Barriers associated with exercise and community access for individuals with stroke. *Journal of Rehabilitation Research and Development*, 45(2), 315-322. doi: 10.1682/JRRD.2007.02.0042
- Russell, K. L., & Bray, S. R. (2009). Self-determined motivation predicts independent, home-based exercise following cardiac rehabilitation. *Rehabilitation Psychology*, 54(2), 150-156. doi: 10.1037/a0015595
- Ryan, M. R., & Deci, L. E. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychological Association*, 55(1), 68-78. doi: 10.1037//0003-066X.55.1.68
- Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experiences of living with stroke: A qualitative meta-synthesis. *Journal of Rehabilitation Medicine*, 40(8), 595-602. doi: 10.2340/16501977-0238
- Sandeep, K., Selim, H. M., & Caplan, R. L. (2010). Medical complications after stroke. *The Lancet Neurology*, 9(1), 105-118. doi:10.1016/S147-4422(09)70266-2

- Saunders, H. D., Greig, A. C., & Mead, E. G. (2014). Physical activity and exercise after stroke: Review of multiple meaningful benefits. *Stroke*, *45*(12), 3742-3747. doi: 10.1161/STROKEAHA.114.004311
- Shurrab, M., Crystal, E., O'Donnell, D., Navare, H., Neves, P., Khatib, R., Lashevsky, I., & Newman, D. (2017). The gap between indicated and prescribed stroke prevention therapies in a high-risk geriatric population. *Journal of Interventional Cardiac Electrophysiology*, *48*(3), 261-266. doi: 10.1007/s10840-017-0223-0
- Silva, K. J., Vila, C. V., Ribeiro, F. M. M., & Vandenberghe, L. (2016). Survivors' perspective of life after stroke. *Open Journal of Nursing*, *18*(1). doi: 10.5216/ree.v18.34620
- Smith, E. E., Mountain, A., Hill, D. M., Wein, H. T., Blacquiere, D., Casaubon, K. L., Linkewich, E., Foley, N., Gubitza, G., Simard, A., & Lindsay, M. P. (2020). Canadian stroke best practice guidance during the covid-19 pandemic. *Canadian Journal of Neurological Science*, 1-5. doi: 10.1017/cjn.2020.74
- Sturm, W. J., Dewey, M. H., Donnan, A. G., Macdonell, A. R., McNeil, J. J., & Thrift, G. A. (2002). Handicap after stroke: How does it relate to disability, perception of recovery, and stroke subtype? *Stroke*, *33*(3), 762-768. doi: 10.1161/hs0302.103815
- Sugavanam, T., Mead, G., Bulley, C., Donaghy, M., & Wijck, F. (2012). The effects and experiences of goal setting in stroke rehabilitation: A systematic review. *Disability Rehabilitation*, *35*(3), 177-190. doi: 10.3109/09638288.2012.690501
- Sun, Y., Boots, J., & Zehr, E. P. (2015). The lingering effects of a busted myth: False time limits in stroke rehabilitation. *Applied Physiology, Nutrition and Metabolism*, *40*(8) 858–861. doi: 10.1139/apnm-2014-0523.

- Taule, T. & Raheim, M. (2013). Life changed existentially: A qualitative study of experiences at 6-8 months after mild stroke. *Disability and Rehabilitation*, 36(25), 2107-2119. doi: 10.3109/09638288.2014.904448
- Taule, T., Strand, I. L., Skouen, S. J., & Raheim, M. (2015). Striving for a life worth living: Stroke survivors' experiences of home rehabilitation. *Scandinavian Journal of Caring Sciences*, 29(4), 651-661. doi: 10.1111/scs.12193
- Teasell, R., Mehta, S., Pereira, S., McIntyre, A., Janzen, S., Allen, L., & Viana, R. (2014). Time to rethink long-term rehabilitation management of stroke patients. *Topics in Stroke Rehabilitation*, 19(6), 457-462. doi: 10.1310/tsr1906-457
- Torriani-Pasin, C., Palma, G., Makhoul, P. M., Antonio, A. B., Lara, R. A., Silva, A. T., Caldeira, F. M., Junior, P. R., Domingues, L. V., Freitas, B. T., & Mochizuki, L. (2021). Adherence rate, barriers to attend, safety, and overall experience of a remote physical exercise program during the covid-19 pandemic for individuals after stroke. *Frontiers in Psychology*, 12(1). doi: 10.3389/fpsyg.2021.647883
- Wagner, C. C., & McMahon, T. B. (2004). Motivational interviewing and rehabilitation counselling practice. *Rehabilitation Counselling*, 47(3), 152-161. doi: 10.1177/00343552040470030401
- Walker, J. (2012). The use of saturation in qualitative research. *Canadian Journal of Cardiovascular Nursing*, 22(2), 37-46.
- White, H. J., Gray, R. K., Magin, P., Attia, J., Sturm, J., Carter, G., & Pollack, M. (2012). Exploring the experience of post-stroke fatigue in community dwelling stroke survivors: A prospective qualitative study. *Disability and Rehabilitation*, 34(16), 1376-1384. doi: 10.3109/09638228.2011.645111

- Wiley, J. (2020). The global impact of covid-19 on acute stroke care. *Neuroscience and Therapeutics*, 26(1), 1103-1105. doi:10.1111/cns.13442
- Winn, S. C., Chisholm, A. B., & Hummelbrunner, A. J. (2014). Factors affecting recruitment and retention of rehabilitation professionals in northern Ontario, Canada: A cross-sectional study. *Rural Remote Health*, 14(2619).
- Young, J. (2007). Review of stroke rehabilitation. *British Medical Journal*, 334(86). doi: 10.1136/bmj.39059.456794.68
- Zamawe, F. C. (2015). The implication of using NVivo software in qualitative data analysis: Evidence-based reflections. *Malawi Medical Journal*, 27(1), 13-15.
- Zhao, J., Li, H., Kung, D., Fisher, M., Shen, Y., & Liu, R. (2020). Impact of the COVID-19 epidemic on stroke care and potential solutions. *Stroke*, 51(7), 1996-2001. doi: 10.1161/STROKEAHA.120.030225