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# Experience of Young Stroke Survivors in a Community-Based Peer Support Group

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Experience of Young Stroke Survivors in a  
Community-Based Peer Support Group

by

Tiffany Danette Morin

A THESIS

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## Abstract

Purpose: The purpose of this study was to explore the experiences of young stroke survivors (YSS) participating in a community-based peer support program in Calgary, Alberta. There is a lack of research on peer support groups facilitated by YSS themselves, and on the impact of peer support on the health and wellbeing of stroke survivors under the age of 50.

Methods: This qualitative case study project was guided by Critical Disability Studies and included five semi-structured interviews with YSS in Calgary, Alberta. Participants were between the ages of 18-50 and had attended at least two YSS peer support activities in the past three years. Following the principles of community-based research, support for this research was provided by the Stroke Recovery Association of Calgary to co-create the research question, methods, recruitment, and analysis of results, along with guiding the development of the implications and recommendations.

Results: Three main themes and six sub-themes were identified from the interviews as follows:

- 1) Feeling *normal*;
  - 1a) What is *normal* anyways?;
  - 1b) Why does there need to be a *new normal*?;
- 2) Connection through lived experience;
  - 2a) Shared life and stroke experiences;
  - 2b) Mixed feelings when meeting with other survivors; and
- 3) Perceived benefits of attending the peer support group;

3a) Being accepted by others;

3b) Opportunities for social interaction.

Conclusion: This case study demonstrated that there continues to be value in recommending peer support to YSS, especially grassroots groups that are led and facilitated by those with lived experience. Participants experienced connection through shared experiences, as well as supported each other to navigate a world that caters to people who fit societal norms and often leaves them feeling isolated and alone.

Keywords: young stroke survivors, stroke, peer support, community engagement

## **Preface**

This thesis is original, unpublished, and independent work by the author, T. Morin. The interviews reported in Chapters 3-5 were covered by the Ethics Certificate number REB21-0412, issued by the University of Calgary Conjoint Health Ethics Board for the project “Experience of Young Stroke Survivors in a Community-Based Peer Support Group” on June 9, 2021. I would like to acknowledge the assistance of a copy editor, in accordance with the University of Calgary’s writing guidelines, for their valuable contribution in ensuring the clarity and coherence of the final draft of this thesis.

## **Acknowledgements**

Firstly, I would like to acknowledge that the University of Calgary is located on the traditional territories of the people of the Treaty 7 region, and the Metis Nation of Alberta Region 3 (which I am a member of). This thesis was written, and research was conducted, as a guest on this territory. I am grateful for the opportunity to live, play, learn, and work on these beautiful and sacred lands. This project would not have been possible without an amazing community of support. I acknowledge that without the Stroke Recovery Association of Calgary and the Young Stroke Survivor peer support group being willing to collaborate with me, this research project would not have been possible. Also, having a thesis committee who was supportive, knowledgeable, and kind with their feedback made the research process doable – thank you Dr. Katrina Milaney (supervisor), Dr. Joanna Rankin, and Dr. Sean Dukelow.

More than half of my graduate school experience was during the COVID-19 pandemic, and I need to acknowledge some very important social supports. These supports include Andrei (best partner that I could have ever asked for), Tina, Sara, Neelam, Jessica, & Lisa (and so many others). My Alberta Health Services rehabilitation colleagues have been a great support through all of this, a big thank you to all of you. My circle family (Elders, Indigenous graduate students, Indigenous faculty, and staff) was a lifeline many days. I met with them every second Friday through 2021, 2022, and the beginning of 2023.

Special thanks to my oncology team through the Tom Baker Cancer Centre who treated me through 2022 (surgery and chemotherapy). You literally saved my life.

Last, but not least, to my family that have been with me on this journey of a first-generation graduate student (Mom, Dad, Byron, Liesel, Shauna, Josh, Greg, Bronwyn, Bear, Spencer, Cohen) – love you all!

## **Dedication**

This thesis is dedicated to all the young stroke survivors that I have had the absolute pleasure and honour to work with over the years through the Calgary Stroke Program. Thank you for trusting me to be on your team, sharing your stories with me, and for showing incredible strength and resilience.



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## **Chapter 1.0 Introduction**

This master's thesis aims to describe the experiences of young stroke survivors (YSS) in Calgary, Alberta who have participated in a community-based grassroots peer support group, led by the survivors themselves. Survivor-led peer support is not uncommon; however, it has not been reported on in stroke recovery research. I have several years experience working with YSS as a rehabilitation professional, and I strive to approach this work with compassion and empathy for the experiences of YSS.

My thesis begins with a general background about the incidence of stroke, the specific needs of YSS, background on peer support approaches, and stroke recovery and rehabilitation. In addition, I provide a review of health literature about YSS, peer support, and the intersection of these two. Next, I introduce Critical Disability Studies (CDS) and explain why a CDS lens was used to guide the development of the research questions, methods, and analysis process. A CDS approach aligns well with peer support approaches, where shared experiences are seen as an important part of stroke recovery and healing. Furthermore, CDS prioritizes people with lived experience as experts in their health and social needs. Following the literature review, I share the results of a thematic analysis from the case study interviews, which is subsequently followed by discussion, implications of the findings, and recommendations for future research.

Results from this study are applicable to the practice of stroke rehabilitation professionals within the Calgary Stroke Program and beyond. By making the voices of those participating in community-based peer support front and centre, we are ensuring that they are heard and that their experiences are valued.

A CDS lens challenges every aspect of the stroke recovery model, including its language and expectations of people living with stroke. For example, at what point after someone experiences a stroke do healthcare and social support providers start providing support around living with impairments and “come to accept functional limitation without absorbing a sense of shame and inferiority?” (Gill, 2001, p. 354). There is tension between CDS and the medical model in terms of recovery. Recovery is typically understood within the medical model as returning to *normal*, whereas in CDS there is less preoccupation with being *normal* and more focus on living with an impairment. Recovery, in the medical model, is understood as a medical experience rather than something that informs an individual’s whole identity or way of understanding their place in society. When I talk about stroke recovery in this thesis, it is in the context of a medical understanding, and I am referring to the improvement or elimination of neurological and functional impairments from a stroke (Cotoi et al., 2018), and am not subscribing to a definition of *normal* that excludes ongoing effects following recovery. Recovery is not a word that is typically used in CDS because of the association with the medical aspect; however, I am both a health professional and a CDS scholar, therefore, the use of the word recovery in this thesis is referring to the process of healing after a stroke. This is not the only way I understand what stroke survivors live through after their stroke. Terms like *normal* and *recovery* will be discussed in more detail throughout the thesis. Understanding stroke recovery as more than just a medical process is a novel way to explore YSS and peer support from what is traditionally found in the stroke recovery literature.

The next section of this chapter will help build the rationale and justification for the need to study the experiences of YSS and peer support using a qualitative perspective. I define terms that are used throughout this thesis, as well as introduce the rehabilitation process and current programs that exist in order to describe the context of stroke recovery for young people in particular.

## **1.1 Incidence of Stroke in Canada**

In Canada, every 9-10 minutes someone will have a stroke. Over 62,000 Canadians have a stroke each year and there are over 800,000 adult stroke survivors in Canada (Government of Canada, n.d.; Heart & Stroke, 2018). The rate of strokes occurring in people under the age of 50, or YSS, has been rising around the world (Lawrence, 2010; Ramirez et al., 2016; Shipley et al., 2020). According to Heart & Stroke (2017), these rates are growing faster than rates for older adults. More specifically, it is said that “four out of every 100 strokes happen in people ages 18-45” (Campbell et al., 2015). Researchers predict that the rates of young adults having strokes will “double in the next 15 years” (p. 5). Due to advances in stroke care, we can expect that approximately 80% of people will survive a stroke. As Campbell et al. (2015) suggest, “Together this is resulting in more Canadians living with the effects of stroke and requiring services and support as they recover, especially those that return home or to a community setting” (p. 2). As such, there is an urgency to continue to promote and support research in stroke recovery.

### **1.1.1 Young Stroke Survivors**

The social and community needs of YSS are not always met in a world where strokes have been traditionally recognized as an older person’s illness. For the



purposes of this study, YSS are between the ages of 18-50, as they are often in the early or mid stages of their careers, raising young families, furthering their education, and/or having active social and community lives (Daniel et al., 2009; Kapoor et al., 2019; Ramirez et al., 2016). Navigating these important life events when recovering from and living with impairments following a stroke can be a challenge. This may include seeing the world from a different perspective, especially if the individual self-identified as ‘able-bodied’ prior to their stroke. It can be a significant life-changing experience for some people when they discover that living with new impairments in their communities, cities, and towns is much different than they thought it would be (Daniel et al., 2009; Muller et al., 2014). Experiencing a stroke at a young age means that survivors have many years ahead of them living with the effects of a stroke (Cotoi et al., 2018). The needs of YSS are unique, and they require a different approach to recovery than the ‘traditional’ older stroke survivor who may be in a different stage of life including retirement and/or without children living at home (Lawrence, 2010; Tan & Kirshner, 2021).

Table 1 shows data between 2017-2021 from Alberta and Calgary and the number of people between the ages of 18-50 who have had a stroke in the past five years. This data was provided to me by JS, a senior analyst with Alberta Health Services. These numbers further demonstrate the uniqueness of YSS as they make up less than 10% of all stroke survivors in our city and province.

Table 1: Number of Albertans and Calgarians That Have Had Strokes (2017-2021)

<b>Alberta (Ages 18+)</b>	<b>Alberta (Ages 18-50)</b>	<b>YSS in Alberta (%)</b>
22,049	1,942	8.8%

<b>Calgary (ages 18+)</b>	<b>Calgary (ages 18-50)</b>	<b>YSS in Calgary (%)</b>
7,716	694	8.9%

Includes hemorrhagic and ischemic strokes. Excludes transient ischemic attacks (TIAs).

1.1.2 Health and Social Implications for Young Stroke Survivors

The health implications faced by YSS are different from the older adult stroke survivor. Physically, they generally have positive recovery outcomes related to self-care and mobility, up to 95% in some studies (Black-Schaffer, 2018; Kapoor et al., 2019; Varona et al., 2004). The challenges arise in areas such as quality of life, returning to preferred social activities, cognitive impairments, and difficulty returning to work (Black-Schaffer, 2018; Kapoor et al., 2019; Maaijwee et al., 2014). Some studies have reported up to 48% of YSS identify depression symptoms (Maaijwee et al., 2016), while 35-60% of YSS report cognitive impairments (van Rooij et al., 2014; Maaijwee et al., 2014). Moreover, YSS are more likely to withdraw from community-based social activities than older adult stroke survivors (Daniel et al., 2009; Keating et al., 2021).

Compared to older patients, YSS are more readily offered advanced treatments such as “the most aggressive and technologically advanced rehabilitation treatments because of their lesser burden of comorbidity and prior disability and, therefore, their greater tolerance and lower risk of complications” (Black-Schaffer, 2018, p. 746). Decision-making around treatment is challenged by CDS as the “burden” of someone’s health outcomes should not determine whether that medical treatment is offered or prioritized, while challenging the idea that disability of itself is a burden (Drake, 2001). The value of someone’s life based on whether they cost the medical system more or

less, does not align with CDS (Drake, 2001). YSS also tend to get more time on rehabilitation units and are discharged back to the community at a higher rate than older survivors (Black-Schaffer, 2018). The uniqueness of YSS comes up in discussion around cost of care, both for the medical system and for the survivor personally. There is often a loss of productivity, which impacts their lifelong earnings and potentially the lifelong earnings of their caregivers. According to Taylor et al. (1996) and Mittmann et al. (2012), this cost of care can vary between types of strokes and is heavier early on in care (hospitalization and rehabilitation), but long term over the life span of all stroke survivors it has been estimated to cost Canadian society around \$857 million (Mittman et al., 2012, p. 794). This implies that YSS cost the health system more due to living a longer life with their stroke impairments. The measurement of productivity is another example of the debate between the medical model and CDS approach. Similar to the idea of burden, as previously discussed, a CDS lens rejects the preoccupation with cost and instead considers the burdens and costs that the person with the impairment has to deal with within their *new normal* (Drake, 2001).

### 1.1.3 Stroke Rehabilitation

Stroke rehabilitation is a medical process, grounded in the medical model, that provides treatment and education and supports the recovery process of impairments after someone has a stroke. The Calgary Stroke Program outlines the rehabilitation path that one may take if they have a stroke in Calgary specifically (Appendix A). The rehabilitation path includes three sections: 1) recovery starts; 2) return to community; and 3) recovery continues. Support groups fall into the 'recovery continues' portion of the journey, which includes the Stroke Recovery Association of Calgary's (SRAC) YSS

group. After an individual accesses the rehabilitation services within the public health system including inpatient rehabilitation, early supported discharge, and/or outpatient rehabilitation, many are still living with impairments from the stroke. At this point, medical supports include follow-up appointments with physicians and specialists, private therapy, or a community non-profit organization that may provide some community integration support. It is often during this phase that a survivor may try to connect with others who are living with stroke in their community.

The Canadian Heart and Stroke Foundation has identified best practice guidelines for stroke rehabilitation in the *Evidence-Based Review of Stroke Rehabilitation* (EBRSR), currently on its 18<sup>th</sup> edition. The EBRSR includes reviews of over 4,500 studies and 2,170 randomized control trials to develop the best practice guidelines. The chapter on Rehabilitation of Younger Patients Post Stroke (Cotoi et al., 2018) states that “young patients are interested in connecting with others who share similar experiences” (p. 37), and that they “require time to come to terms with having a stroke” and the changes that come with that, such as “physical abilities, work, family, and social life” (p. 37). The conclusions from the EBRSR support the aims of this research project in the following ways:

- “Young patients need to be connected with support organizations and individuals with similar experiences.
- Young patients tend to have unique psychosocial and supportive needs post stroke rather than specific health concerns”.

(Cotoi et al., 2018, p. 37).

These conclusions are further supported by the 6<sup>th</sup> update of the *Canadian Stroke Best Practice Recommendations for Transitions and Community Participation following Stroke* (Mountain et al., 2020). Recommendation 1.2.iii states “People with stroke, their families, and caregivers should be provided with information about peer support groups in their community where available, descriptions of the services and benefits they offer, and be encouraged to consider participation” (p. 794). Between these two guidelines for stroke rehabilitation, there is evidence that peer support is an important part of stroke recovery. The results from this research study will meaningfully demonstrate the experiences of a small group of YSS who participate in the community-based peer support group in Calgary, Alberta.

## **1.2 Definitions**

*Stroke survivor* – The SRAC has declared this the preferred language to describe an individual who has had a stroke and survived.

*Stroke* – There are two main types of strokes: hemorrhagic and ischemic. Hemorrhagic stroke “is caused when an artery in the brain breaks open. The interrupted blood flow causes damage to your brain. High blood pressure weakens arteries over time and is a major cause of hemorrhagic stroke” (Heart & Stroke, n.d.). An ischemic stroke “is caused by a blockage or clot in a blood vessel in your brain. The blockage can be caused when a substance called plaque builds up on the inside wall of an artery” (Heart & Stroke, n.d.).

*Young stroke survivor* – In the literature, YSS can range in age from 18 to 65. For the purpose of this study, YSS includes anyone between 18-50 who has had a stroke. The focus was on YSS who were at a similar stage of their life such as raising young

families, early to mid career, and/or pursuing further education (Kapoor et al., 2019; Leahy et al., 2016).

*Peer support* – A common definition of peer support is that one person with lived experience, in this case having a stroke, connects with another person who has gone through a similar experience. The Canadian Mental Health Association describes peer support as “using collective wisdom to help each other” (n.d.). This exchange between two people, or a group, is usually based on instilling hope through positive self-disclosure and demonstrating that “it is possible to go from being controlled by the illness to gaining some control over the illness, from being a victim to being the hero of one’s own life journey” (Davidson et al., 2012). Connecting with others with a similar experience can provide experiential knowledge that can be helpful while recovering from and living with stroke such as navigating day-to-day life, overcoming stigma and discrimination, and generally navigating the complex social and human service systems (Levy et al., 2019; Lund et al., 2018).

*Normal* – Davis & Bradley (1996) discuss the concept of *normal* in the medical system as an expected state, ordinary finding, a defined standard, and a description of the ideal, but argue there is so much variability and frailty in human beings that it is hard to define *normal*. CDS challenges that there is a universal standard for what is considered *normal* or desirable in terms of ability or health. Instead, CDS recognizes that people have diverse abilities, experiences, and identities, and these differences should be valued and accommodated rather than pathologized (Goodley, 2017; Oliver & Barnes, 2012). This threads into the idea that *normal* is socially constructed and

politically charged and reflects broader power dynamics and social hierarchies (Davis, 2001; Goodley, 2017; Oliver & Barnes, 2012).

*New normal* – For the purpose of this study, *new normal* will be used to refer to adjustment after a significant health incident such as a stroke. Recently, Wenzel et al. (2021) discussed *new normal* as the process of establishing new roles, new routines, and a new purpose after a stroke. Goodley (2017), a disability studies scholar, uses *new normal* as an explanation for when someone adjusts to a loss. Disability studies challenges the idea of a *new normal* and asks why the individual, not society, needs to adjust, a concept that will be discussed further in this thesis.

### **1.3 Peer Support**

By utilizing “non-hierarchical, reciprocal relationships” (Heisler, 2006, p. 8), peer support has been shown to support positive health outcomes. Within the healthcare system, a hierarchical power differential exists between patients and healthcare clinicians, but when an individual connects with someone who has the same lived experience, and when the reciprocal nature of that relationship happens, it can potentially enhance self-management and improve health outcomes (Heisler, 2006).

There are several research projects conducted on peer support with stroke survivors (Kessler et al., 2014; Levy et al., 2019); however, most studies have focused on groups that were hospital/facility-based (Muller et al., 2014), focused on older survivors and their caregivers (Golden et al., 2019), facilitated by clinicians (Lund et al., 2018), and/or are short-term in nature (Sadler et al., 2017). Furthermore, Lawrence (2010) completed a systematic review and found that YSS want to speak and connect with each other, suggesting that referring to support groups should be a priority for

professionals supporting the recovery process. When reviewing the literature on the topic of YSS participating in community-based peer support groups, I was unable to find anything on groups that were solely facilitated by the survivors themselves. Thus, the research question guiding this study is: *What is the experience of young stroke survivors who participate in a community-based peer support group that is solely led by the survivors themselves?*

#### **1.4 Impact of COVID-19 on Study Design**

Initially, this study was going to include observations of the YSS group in action, followed by individual in-person interviews with approximately 5-7 members of the group. In March 2020, the COVID-19 pandemic halted these plans. No observations of the YSS group were conducted because the group discontinued meetings. In addition, the individual in-person interviews were adapted to virtual Zoom interviews instead.

The SRAC found the past three years to be challenging as they were unable to actively support their members the same way as they had pre-pandemic because of public health rules related to physical distancing. Other peer support groups with professional supports such as the March of Dimes (March of Dimes, n.d.) and the Stroke Recovery Association of British Columbia (SRABC, n.d.) were actively running and supporting their members through the COVID-19 pandemic with virtual programs. At the time of this writing, in-person peer support activities through the SRAC were starting to resume once again.

#### **1.5 Positioning Myself**

Taking time to position myself in this research project is important. According to Holmes (2020), a researcher's assumptions about world views, the nature of



knowledge, and nature of humans impacts where they are coming from when conducting research. It can influence “how research is conducted, its outcomes, and results” (p. 2). The concept of being an insider and an outsider is common within qualitative research.

I am an insider because I work in the Calgary Stroke Program as a recreation therapist in an outpatient rehabilitation program through Alberta Health Services. I am an outsider because I am not a YSS and have never had that specific lived experience; however, I have experienced my own severe health challenges. I was diagnosed with ovarian cancer in 2018 and have my own personal health experiences with the healthcare system and recovery. I continue to live with cancer, which includes regular ongoing involvement with the healthcare system (e.g., major surgery and chemotherapy in 2022, regular follow-ups with my medical team), not unlike the YSS that participated in this study.

Through my cancer recurrence in 2022, I was fortunate to have my own peer support experience that also informs my positioning in this study. I have a rare type of ovarian cancer and it can be challenging to find others with a similar lived experience. With that in mind, there is an incredible group of people from around the world that have found each other on Facebook and have a very active online peer support group. I am grateful to be a part of that group and for the support I receive, and I am also able to provide support to other people who have this rare form of cancer. Additionally, I am part of a Canada-wide online support group with young people who have all types of ovarian cancer. We meet online once per month and maintain an active WhatsApp group chat. The experience of connecting with people who have a similar lived

experience has been important to me and has helped me as I navigate my 'new normal' (Canadian Cancer Society, n.d.) as a CDS scholar and someone living with cancer. During the final semester of my graduate studies, I was a participant in the Alberta Cancer Exercise (ACE) program at the University of Calgary. This provided me yet another opportunity to connect with others who have recently experienced treatment for different types of cancers. We would see each other twice per week over 12 weeks and supported each other with improving our strength, cardiovascular health, and fatigue management.

Through my practice as a recreation therapist within the Calgary Stroke Rehabilitation program, I have had many conversations with YSS over the past 11 years about their experiences with supports and services. The desire to connect with others who have lived experience comes up often. I have heard many stories of people feeling alone and not realizing that there are others out there who feel the same way, and who have had related experiences. For those who have connected with peers, outside of their professional rehabilitation and medical team, it has allowed them to step away from the medical environment with strong power differentials (Goodley, 2017; Saxton, 2018) and experience more autonomy. Through my personal and professional experiences, I have observed that identities are acquired and changeable, and they can shift within the diverse health systems and cultures that currently exist. It is the paucity of research of the unique experiences of YSS that drove me to take up this study. I have seen how the experiences of YSS can be impacted by power differences that exist between professionals and patients, and how connecting with others with lived and related experience can be a source of strength.

My position as a disability studies student, both for my undergraduate degree and my master's degree, who also works in the medical system, is unique. It brings some complexities that make me question and reflect on how I practice as a rehabilitation professional and how I learn and understand CDS in the university and professional environment. This complexity adds a unique lens to my thesis that I was not expecting initially, and has caused me to adjust how I practice, how I communicate with my colleagues, how I advocate for and communicate with my clients, and how I engaged with this research project. The tensions that I feel as a professional in the medical system and a CDS scholar are challenging. I am continually grappling with the conflict and debates around *normal*, *new normal*, *recovery*, *burden*, and so forth. This tension is an important catalyst for why I took up this research in the first place; to find my footing in the rehabilitation field, specifically as a recreation therapist with an education in CDS.

### **1.6 Community Advisory Committee**

I had ongoing conversations with, and support from, various advisors to help develop this study. My advisory committee started years ago when I first started to think about research in this area and had met with the then leader of the YSS peer support group. This connection led to the addition of more advisors through the SRAC board of directors and past YSS peer support group leaders. Between 2020-2023, I regularly checked in with members of this advisory committee, attended Zoom meetings with them, and was guided by their experience and the expertise of their lived experiences and leadership in peer support. Throughout the project, I also reached out to and was

advised by the Heart and Stroke Foundation of Canada, the March of Dimes After Stroke Program, and stroke peer support researchers in Canada.

### **1.7 Theoretical Approach**

This study was informed by CDS in its conceptualization and development of the research questions, study design, and analysis of results. A CDS approach was chosen as it provides a different and unique lens than what currently exists in the stroke literature, most of which is grounded in more medical approaches to recovery and rehabilitation. By applying a CDS lens on the experiences of YSS, we can better understand the complexities of living in a society that is not necessarily designed for an individual living with stroke, and specifically a young person who may have different societal demands placed on them. Scholars and researchers of CDS argue that impairment is distinct from 'disability', with an impairment being a limitation on the body, and disability being a societal concern. The medical model views disability as a problem (impairment) that exists within the person (Oliver & Barnes, 2012). The problem can be 'solved' through medical treatment and therefore, medical research focusses on advancing treatment and cures. Disability scholars have criticized the 2001 World Health Organization's International Classification of Functioning, Disability and Health (ICF), which is often referred to in stroke rehabilitation. The ICF is meant to support both medical and social models, and introduced a bio-psychosocial model instead. Goodley (2017) shares that the criticism partly comes from the vagueness of the model, and that it doesn't capture the complexities of impairments and disability, ignoring "definitions developed by disabled people's organizations" (p. 20). Goodley (2017) explains that complexities include "culturally specific conditions on which impairment, disability and

disablism are created” (p. 20). CDS scholars argue that people are not only disabled by their impairment, but more so by the social attitudes, institutional norms, and the policies that govern service delivery (Fenney, 2016; Goodley et al., 2019). Researchers using CDS are interested in positing alternatives to current understandings, interventions, and policies by including lived experience experts in research and decision making in terms of ‘what they need’. Thus, CDS is a different theoretical lens to take in the stroke recovery literature.

### **1.8 Thesis Layout**

Chapter 2 includes a literature review on three areas that are important to reflect on for this thesis:

- 1) YSS;
- 2) the concept of peer support; and
- 3) current research on stroke peer support.

Chapter 3 describes the methods and theoretical stance, namely CDS, used to guide the research and analysis of results found in Chapter 4. Chapter 5 includes a discussion and reflection on the results of the study, followed by discussing future research possibilities and dissemination plans. This layout will provide readers with a comprehensive understanding of the research project and future implications.

The purpose of this project is to understand the peer support experience in a unique grassroots group in Calgary. Using a case study methodology, guided by the stories of five YSS and informed by a Critical Disability Studies lens, I posit that peer support for YSS contributes to building strong connections, benefits, and support for navigating their new world together.

## Chapter 2.0 Literature Review

There is a paucity of published research on peer support for YSS. Wan et al. (2021) conducted a systematic review and meta-analysis of studies that included adult participants who had experienced a stroke, and used peer support as a key term, and only found 11 research publications between 2009 – 2020 on the topic of peer support interventions on physical and psychosocial outcomes among stroke survivors. Wan et al. (2021) concluded that physical and psychosocial benefits may be an outcome of stroke survivors participating in peer support; however, social participation and quality of life outcomes were inconclusive. Wan et al. (2021) sets the stage for this literature review and as such, the following is divided into three main sections:

- 1) YSS;
- 2) peer support; and
- 3) peer support for stroke survivors.

The first section of the literature review describes what is known about the experiences of YSS and their unmet needs, such as supports for returning to work, managing relationships, and returning to social roles, as well as emotional support, and age-appropriate rehabilitation. The second section outlines how peer support has been known to foster a supportive environment that empowers people living with a variety of health conditions to live a good life, particularly in the field of mental health. Concerns about theories and methods of peer support, as well as its growth of the field of mental health and unintended consequences of peer support, will be addressed in this section of the review. The third section of the literature review will focus on three peer support programs that were specifically implemented for stroke survivors. By the end of this

literature review, it should be clear why this case study of the YSS peer support group is worth exploring further for its uniqueness and contribution to the lives of YSS in Calgary, Alberta.

## **2.1 Young Stroke Survivors**

Research shows YSS are a growing demographic (Cotoi et al., 2018; Tan & Kirshner, 2021), and existing research focuses on survivor relationships (Buschenfeld et al., 2009; Quinn et al., 2014), social consequences (Daniel et al., 2009; Teasell et al., 2000), and survivor priorities and goals (Williams et al., 2019). These research topics are slightly different than the research on peer support for older stroke survivors; this aligns with the uniqueness of this group. I address three topics in this section: 1) young people coping with stroke (Kuluski et al., 2014); 2) preferred methods of meeting their needs (Keating et al., 2021); and 3) young women having a stroke (Leahy et al., 2016). These three articles were selected as together they will paint a broad picture of the experience of young people having strokes, and at the same time they still cover the main topics of relationships, social needs, and priorities, that currently exist in the research on YSS.

### **2.1.1 Young People Coping with Stroke**

Kuluski et al. (2014) explored the impact of having a stroke at a young age (55 years old and younger) and what that meant to participants' lives, their families, their work situations, and how they managed to cope and recover from this life-changing event. Semi-structured interviews were conducted with 17 stroke survivors who were asked to share their stroke stories. Two main themes were identified. First, participants spoke of an altered sense of self, including sub-themes of loss of identity, family

disruption and role change, and loss of valued activities. The second theme was an adapted sense of self, with sub-themes of seeking external support, restoring normality and positive reflection. The researchers touched on some implications for stroke rehabilitation, such as returning to work, which is often a high priority for YSS, mental imagery to improve motor function, and ongoing emotional support. The researchers concluded that YSS have their lives interrupted in a variety of ways including career, family, and social life, yet despite this, the theme of resilience also emerged.

### 2.1.2 Preferred Methods of Meeting Their Needs

A recent article by Keating et al. (2021) investigated the preferred methods of meeting the needs of YSS (ages 18-55). Participants were asked to complete an online survey and a variety of questionnaires. First, there was a demographic and stroke history questionnaire, followed by a Young Stroke Needs Screening Tool (developed at the Florey Institute of Neuroscience and Mental Health), a questionnaire about how YSS wanted their needs to be addressed, and finally the modified Rankin Scale (mRS), which measures one's level of functional independence.

Following analysis of survey data using a series of logistical regressions, two main findings were identified. First, "young stroke survivors are receptive to methods of meeting many of their needs outside the traditional healthcare setting and do not always prefer to see a clinician to meet their needs", and second, "these preferences are not uniform" (p. e1707). YSS are not a group that can follow a "one-size-fits-all" approach to care. The researchers suggest having experts that specialize in treating YSS, supporting them in self-management strategies when they are ready, compiling simple evidence-based lists of tips or articles to read, and offering specialized peer support



groups for YSS. In addition, YSS tend to be more open to online service delivery and accessing resources online. The authors conclude “the experience of having a stroke cannot be characterized only in terms of medical diagnoses or functional disability” (p. e1709).

### 2.1.3 Young Women Stroke Survivors

Finally, Leahy et al. (2016) explored the experiences of young women who have had a stroke. Twelve participants were invited to share their stroke story and how a stroke has impacted their lives in an interview. They were guided through topics such as sense of self, emotional experiences, and interactions with others. Using an interpretive phenomenological analysis, the researchers identified four themes: stroke as an illness of later life: ‘obviously it’s for older people’; post-stroke selves; a desire for peer support; and the impact of stroke on relationships. The authors note the need to improve public awareness of young people having strokes so that services do not get delayed, facilitate social support groups, access more virtual treatment options, and ensure that stroke rehabilitation programs are age-adapted. In addition, peer support and connecting with others who have a similar experience can be an important part of post-stroke life for young stroke survivors.

These three articles on YSS make it clear that they are a unique group, and their needs are different from the traditional older adult who has a stroke. Some of the themes overlapped, including reasons to connect with others, navigating life interruptions, and the recommendation of peer support groups, which helps solidify the findings from these researchers. All articles stated that more research in the area of YSS is needed.

## **2.2 Peer Support (Non-Stroke Population)**

The field of peer support is vast, so finding “general” peer support research can be a challenge. A large amount of peer support research is from the field of mental health as this is where the concept of peer support appears to have originated (Ibrahim et al., 2020). This is also the area where a great deal of advancement of peer support interventions and outcomes can be found. There have been two systematic reviews conducted recently (Ibrahim et al., 2020; Mowbray et al., 2021) on evaluating peer support program influences and outcome measures. In addition, Walker and Peterson (2021) explored the theories and methods underpinning effective research in peer support in relation to chronic disease management. Similarly, Adams (2020) examined the growth of peer support and its unintended consequences within mental healthcare. By exploring these articles, we can get a glimpse of what is currently happening in the world of peer support research.

A review completed by Walker and Peterson (2021) compared a literature review completed in 2011 to an updated review completed in 2019 with a goal of identifying if further research into peer support became more effective and produced better evidence in those ten years. The researchers found that although more randomized control trials (RCT) were conducted, there appeared to be little improvement since 2011. For example, there continues to be “short timeframes, often low numbers, sometimes poor results, lack of definition and theoretical underpinning as well as poor reporting on the training of support group facilitators and no long-term evaluations of health outcomes” (p. 218). Due to this, the authors question current research designs for peer support and identified some questions to consider:

Are we researching the wrong aspects of peer support? Are we expecting outcomes that are not, in fact, the province of peer support such as changes in biomarkers for the severity of chronic health conditions? Is the RCT the correct methodology to apply since it removes variables that might provide useful information about components of peer support? If RCT is to be retained, are there more appropriate indicators to measure effectiveness of peer support than measures of clinical outcomes? Are there more appropriate research designs that will generate robust outcomes; and capture important information about the journeys of ill people who access peer support? (p. 219)

The results of the literature review comparison raised four main areas of concern. First, improved research design. Peer support researchers could improve their design by including definitions, since peer support can have a variety of roles and names, and more clear theoretical input influencing the project design. The second area of concern includes critiques of the RCT. Walker and Peterson (2021) are concerned that RCTs are reductionist and “reduce peer support to predetermined component parts” (p. 221). They suggest that a mixed methods approach is necessary to understand the full effects of peer support. The third area of concern identified was the value of considering peer support as a complex intervention. It is complex due to the nature of operating within healthcare systems but also within broader social structures. This would require more complex thinking around how to design peer support interventions and evaluations of those interventions. Finally, the fourth area that was mentioned is to consider other measures and methodologies. The authors suggest that future peer support research should consider longitudinal studies, more mixed methods (online surveys, semi-

structured interviews, focus groups, process evaluations), and measures such as self-efficacy, health literacy, as well as depression and anxiety scales.

Regardless of all the suggested changes to research from Walker and Peterson (2021), it continues as it has, and according to the authors is “generally disappointing” (p.224). As peer support remains a popular intervention in various areas, the suggestions from this literature review comparison are important for future peer support researchers in order to validate its effectiveness for those living with different health conditions. For the current research project with YSS, the suggestions from Walker and Peterson (2021) are important when looking at future projects. This thesis project is a small qualitative research case study, and according to this article could potentially be an approach to supplement larger research projects examining the effects of peer support.

Similar to the research done by Walker and Peterson (2021), Adams (2020) explored “the inherent tension between institutionalization of peer support and the field’s consumer-based origin” (p.1). The focus for this research was directed towards recovery-oriented mental healthcare, which has seen extensive growth over the years (Adams, 2020). Peer support workers have been working within mental healthcare providing non-clinical support services, and due to this it has become more formalized.

Adams (2020) interviewed 49 peer support workers and stakeholders and found the institutionalization of peer support services has expanded in the field. In this context, institutionalization refers to peer support workers being hired and paid as staff within the healthcare system. In Pennsylvania, as of 2017, there are over 4,700 trained peer support workers in the state and this service can be covered by Medicaid. Adams

(2020) suggests, however, there have been some unintended consequences of institutionalizing peer support. First, the scope and nature of peer support work has fundamentally changed. Some of the data suggested that peer support is less flexible than it used to be, there is less emphasis on the needs of the individuals and more emphasis on paperwork due to the billing process that has to happen since involving billable services. There is also criticism that the recovery principles of peer support cannot survive within healthcare bureaucracies and requirements when the role is professionalized. Second, institutionalizing peer support is narrowing the peer support workforce. This limited entry in the field is due to the requirements of peer support workers, such as being able to write a progress note, complete the Certified Peer Support (CPS) training program, and they must have a high school diploma or GED. This excludes many peers from working in the field. Third, there is now a power differential in place that was not there before around the peer support worker and client relationship. This falls under 'professional boundaries' as the peer support workers are paid staff and are trained to maintain these boundaries, which reduces the opportunity to build connections with clients and provide appropriate peer support. Lastly, there is an unintended consequence of stigma and lack of inclusion in the workplace. The authors mention previous research from Chapman et al. (2018) that state "PSWs employed in clinical settings report experiencing more stigma compared to those working within consumer-run organizations" (p. 5).

Adams (2020) concludes that it has been worth exploring the tension within institutionalized peer support versus the consumer-driven grassroots origin of the field, not necessarily saying one is better than the other, but that there are clear differences.

In addition, further discussion is needed on the impact of stigma in a paid peer support role where it is a requirement to disclose one's mental health status. Finally, there are some social inequalities that arise through institutionalization of peer support roles, such as the requirements of being a high school graduate when that can exclude those from marginalized groups.

The reason that this article was included in the literature review was due to the nature of institutionalized peer support versus consumer-driven, or grassroots, peer support. The current study is about a grassroots peer support group, and so we can use comparisons to the institutionalized peer support examples from Adams (2020) to discuss the impact of this group in Calgary on the lives of YSS.

There could have been several articles included in this section, as there is an abundance of research on peer support in mental health, chronic conditions, and many other health-related areas. These two showcased some of the activity around peer support research at the moment, as well as the ongoingness of the trend of institutionalizing peer support in mental health. This is helpful when exploring this case study of a small grassroots peer support group for YSS in order to provide context to the bigger world of peer support research.

### **2.3 Peer Support in Stroke**

Having reviewed the literature around YSS and some of the current developments in peer support, this section will explore the literature around peer support specific to stroke survivors. Research suggests the key features and roles of peer support specifically with group self-management interventions include the sharing of experiences, social comparison, vicarious learning, and increased motivation (Clark

et al., 2020; Golden et al., 2019; Lund et al., 2018; Muller et al., 2014; Sadler et al., 2017; Wijekoon et al., 2020). For the purposes of this literature review and my thesis project, three articles have been included.

First, Muller et al. (2014) examined a hospital-based peer support pilot-program that targeted YSS in a Pennsylvania-based rehabilitation hospital. The program is called Young Empowerment Stroke Support (YESS) program and is intended to “address role facilitation, socialization, and healthy coping strategies through active engagement and client-centred educational topics within a group context” (p. 280). The group was guided by occupational therapy principles and facilitated by occupational therapists. Theories that guided this program included group dynamics, social learning theory, and the Model of Human Occupation.

The YESS pilot program included 13 individuals from the hospital. To be eligible, participants had to be between the ages of 18-65, have had a stroke, be alert, able to communicate (use of assistive devices and other communication tools was allowed), and able to tolerate 60-90 minutes of group activity. They met together nine times over 18 weeks, each session was approximately 90 minutes and had a specific focus, from goal setting and emotional changes to sleep and nutrition. Outcome measures used for the pilot-program included the Stroke Impact Scale (SIS), the Community Integration Questionnaire (CIQ) and a post-group survey.

The post-group survey indicated that participation in the group had a positive impact on coping strategies, and that most participants reported socialization as their favourite part of the group. There was also feedback on the group aspect and that they found the new information, education, and community resources helpful. A few

limitations were mentioned, such as social support of participants (not having access to transportation to attend the group), program evaluation (SIS and CIQ may not have been sensitive enough to capture change or may not have been the best tools to use), and bias around recruitment as the facilitators recruited from their own program and knew many of the participants. It was not clear in the article if the participants had completed their in-patient rehabilitation, if they were out-patients, or if they had completed active rehabilitation. These factors could have also impacted the results of the outcome measures.

As this was the only recent article which examined a peer support group for YSS, it was worth seeing how a program like this was developed and what came out of it. In Calgary, this could perhaps be compared to an education-based group called 'Living with Stroke' which was a six-week group facilitated by the Alberta Healthy Living program through Alberta Health Services. This group has been on hold since March 2020 due to the COVID-19 pandemic, and when enquiring about if it will start back up, I was unable to confirm any information around a return date. Heart & Stroke also offers a Living with Stroke program, but they currently only facilitate it within Quebec. Partner organizations in Canada can use the Living with Stroke program structure and branding if they have someone who is trained in a facilitator to run it. For example, Bluewater Health in Sarnia, Ontario offers the Living with Stroke program to their patients who have had strokes.

The second article, by Lund et al. (2018), evaluates the Lifestyle Redesign® program, which was developed for older adults, but had not yet been implemented with older adults who specifically have had a stroke. This program is based on occupational



science that “emphasizes the connection between human occupation, well-being and health” (p.128), with a focus on the key concepts of doing, being, belonging and becoming (2018). Researchers decided to test out this program with older adults who had experienced strokes and collaborated with six senior centres between 2007-2011 on an RCT.

The groups were offered once per week over nine months. Each group consisted of two to eight participants. The groups involved a variety of methods, such as “peer exchange; didactic presentations; self-reflection; and performing occupations” (p.128). For the study, Lund et al. (2018) sampled participants from these groups, who were part of the larger RCT, had already completed the nine-month program and who had adequate language skills to participate in an interview. Themes from the research included positive experiences in sharing their stroke stories, knowledge exchange, motivating each other, and self-reflection. The group was also found to contribute to the “development of a sense of autonomy, responsibility and control over everyday life” (p.133).

This article does not mention “peer support” per se, but essentially the Lifestyle Redesign® program aligns with similar peer support groups, such as YESS (Muller et al., 2014), and makes relatable conclusions around sense of belonging and meaningful activity with others who have shared experiences. This study is another example of the desire and need for post-rehabilitation stroke groups that bring people together to further enhance their every day lives.

The third article for this section on stroke survivors and peer support comes from Wijekoon et al. (2020) and is the most recent research available on this topic. It is the

most closely related to the current research project. Wijekoon et al. (2020) aimed to explore an outpatient peer support group and the impact on occupational performance, meaning, “activities of daily living, leisure activities, social participation, and sleeping” (p.174). The outpatient peer support group for this study takes place in Toronto, Ontario. It is facilitated by occupational therapists and physiotherapists once per month out of the West Park Healthcare Centre, and they have an average attendance of 30 stroke survivors and caregivers in attendance. The group typically involves a lecture component followed by refreshments where the group members can chat with one another.

This was a qualitative study that included semi-structured interviews with participants of the West Park Healthcare Centre outpatient peer support group. The ages of participants ranged from 49-66 years old. Following interviews with participants, researchers discussed four themes as “finding hope to return to meaningful occupation, a place of belonging, problem-solving occupational concerns, and finding a purpose beyond oneself” (p.176-177). Participants shared that they were “inspired by others” (p. 176), that “connecting with others in a similar situation mitigated feelings of loneliness and isolation in the community” (p. 176), that they “gained new knowledge and skills from peers to participate and find meaning in occupations that had become difficult since their stroke” (p. 177), and that they experienced value in “providing general hope and encouragement to peers” (p. 177). The authors conclude that the positive findings strengthen the support for the use of peer support for stroke survivors. Specifically, it is “not merely a venue for receiving support, but also one for giving hope, encouragement, support, and tangible resources to others” (p.178).

The main difference and theoretical impact between this study and my thesis is around having the group facilitated by healthcare providers. Similarities included participants no longer being involved with inpatient rehabilitation, the sample number of six, and the interview length are also close to what took place in this study. Wijekoon et al. (2020) add something new to the existing literature, in that stroke peer support groups can help stroke survivors “reengage in meaningful occupations, manage their stroke experience, and move positively through recovery” (p. 173).

## **2.4 Summary**

This literature review of eight articles provides background and context on the current state of knowledge about peer support, benefits for YSS, and research-related issues around being able to draw solid conclusions about the ‘best way’ to offer peer support. Tying together research on YSS, peer support, and peer support for stroke survivors together demonstrates research on this topic is lacking. I was not able to find research specifically on grassroots peer support programs for YSS, perhaps because there are not that many that exist, or if they do, they exist separate from the medical and rehabilitation community and ‘fly under the radar’. It would have been interesting to read about the increase of informal peer support for YSS offered through social media, as there are many groups posting about this, but no articles were found. As the YSS population grows, as indicated by the Heart and Stroke Foundation of Canada (2017) and others (Lawrence, 2010; Ramirez et al., 2016; Shipley et al., 2020), the quantity of research in this area will likely also increase.

## **Chapter 3.0 Methodology**

This section provides details about the case study approach including theoretical orientation, participant recruitment, data collection, analysis, rigour, reflection, and ethical considerations. I also include the Community Engagement Strategy that was used with the SRAC. This followed a specific design to respectfully and thoughtfully engage with the stroke survivor community throughout the study.

### **3.1 Theoretical Orientation**

The conceptualization and development of the research questions and study design was informed by CDS, which “explores the complex interplay of social power dynamics, normalization, inclusion/exclusion, accessibility, mobility, identity politics, intersectionality and privilege” (Saxton, 2018, p. 24). Disability theorists agree, arguing that disability should not be seen as an individual ‘problem’, but more so a societal concern where people are ‘disabled’ by barriers within contemporary society (Goodley, 2017; Oliver & Barnes, 2012). Disability theorists challenge traditional theories or conceptions of disability, called medical models, and argue that within these traditional models, disability is pathology, and the ‘solution’ is to fix or cure the individual with the impairment, rather than examine and disrupt structural barriers (Gill, 2001; Goodley, 2017; Oliver & Barnes, 2012). In this way, CDS can be seen as progressing beyond the medical model, and contemporary CDS is founded on theoretical and nuanced interpretations of this. In the medical model, a disabling condition exists within the individual, as their tragic misfortune or ‘sickness’ (Barnes & Mercer, 2001; Gill, 2001; Goodley, 2017; Oliver & Barnes, 2012). It is seen as an internal problem requiring professional or medical interventions to establish, or re-establish, that individual’s

personal potential through cures or treatments to alleviate the disabling condition (Cameron, 2014). The medical model is an individualized approach whereby progress or success is rarely directed at the quality of care or intervention provided. Rather, it becomes a value-laden reflection of the ability or motivation of the disabled individual to get better and become more *normal* (Goodley, 2017; Oliver & Barnes, 2012). In turn, these approaches can serve to diminish a sense of self worth, efficacy, and potential. When an individual has a stroke as a young adult, they will often have to navigate multiple and intersecting interventions while also handling social experiences, such as exclusion, accessibility, and changes to their position, identity and privilege that they have not previously experienced (Kuluski et al., 2014). Furthermore, YSS often spend many hours within a healthcare system that treats their impairment, but may do little to prepare them for the structural barriers and psycho-social and emotional aspects of recovery as they enter back into the 'real world' (Keating et al., 2021). Peer support is a way in which addressing these barriers may be upheld, as after an acquired impairment, such as a stroke, many struggle "to maintain a sense of self-worth in a culture increasingly geared to the myth of non-disabled normality" (Oliver & Barnes, 2012, p. 111). Peer support may provide a source of hope, empowerment, and strength, and when considering the complexities of navigating a new world after a stroke, these would be welcome qualities. The experience of YSS may provoke "deep questions about what it means to be a human being in a contemporary world that is shaped by inequalities" (Goodley, 2017, p. 20). These questions allow one to explore how their experiences, in this case a stroke, are influenced by organizational structures, such as the medical system, and how an individual or a group can be socialized to certain roles.

Understanding the experiences of YSS through a CDS lens in this study means prioritizing the voices and experiences of participants. This creates a space to examine and understand non-traditional and non-medical supports like peer support and how they can play a role in the needs of people who were once, but may no longer fit within an understanding of what is *normal*, and how this aligns with the nature of being *normal* identified in the disability studies literature as noted above. A CDS lens provides a framework that allows an examination of the ‘problem’ of stroke survivors’ recovery from an alternative lens. It also provides the opportunity to look at society at large, and what it is like transitioning into a world where everything has changed for someone after having a stroke.

### **3.2 Community Engagement Strategy**

This study was conducted in partnership with the SRAC; therefore, an engagement strategy was developed early on to build trust and support the strengths of their members. The SRAC board of directors were included in my advisory committee for this project, as were a few of the members at large. To engage with the SRAC, I used the community engagement steps of ‘set and collect’ and ‘reflect and implement’ (Marlett, 2020). This was meant to be an inclusive research project where participants were invited to be a part of the project and not exploited for research purposes. They are the experts of their experiences, and it was important for me to acknowledge that within this project. “When patients and communities are engaged, they take up a shared ownership of the process and are able to take the lead in suggesting and following ideas by noting challenges and alternatives” (Marlett, 2020).

### 3.2.1 Set and Collect

To engage more with the community and reciprocate their openness to participate in this project, I co-designed a membership survey with the SRAC board of directors. The survey supported SRAC in gathering data about their membership and supported organizational goals for their future, including whether or not peer support is a priority. As stated in the book *Grey Matters* (Marlett, 2010), “if participants are going to own the results, they must feel they own the process” (p. 191). Members of the SRAC board of directors co-designed the survey questions and decided what information was most important for them to gather. I arranged virtual co-design sessions for the group to develop open- and closed-ended questions. I provided an educational session on how to build effective surveys and the slides were shared with the board of directors to support the development of the final survey. The Dillman Total Design Survey Method (TDM) (Dillman, Smyth & Christian, 2014) was proposed as the method for survey design. The Dillman TDM involves a structured process to gather information, reduce survey errors, and motivate responses. “The TDM is based on sound research principles and confirms that when attention is paid to administrative detail, high response rates can be achieved” (Hoddinott & Bass, 1986, p. 2366).

### 3.2.2 Reflect and Implement

Once the survey had been administered, the SRAC and I met and reviewed the results together. The board of directors chose to share the results with the SRAC membership in the Fall of 2021. While survey results are not presented as part of this thesis, this process was helpful in establishing trusting relationships (respect), giving me an opportunity to ‘give something back’ to the SRAC (reciprocity), and results from

several of the questions in the survey helped inform the semi-structured interviews. For example, a question around participation in specific activities was used as a prompt during interviews if a participant needed assistance recalling what types of activities had been offered in the past. The locations and time of day of various activities were also used as prompts during interviews. For example, if a participant stated that timing or location of activities was a barrier, I could prompt a bit further around time and location using results from the survey.

### 3.2.3 Community Engagement Strategy Timeline

The following timeline outlines the engagement that was taken with the SRAC starting in January 2020. I had informal discussions with the SRAC and YSS groups prior to this, however, this was the more formal timeline tied directly to the research project itself.

1. Contacted the SRAC, met with the board of directors, confirmed research project.
  - a. Email sent to SRAC board of directors in January 2020.
  - b. I met in-person with the board of directors on February 11, 2020.
  - c. Confirmation of engagement received from the SRAC on February 27, 2020.
2. Scheduled engagement meetings into Summer 2021.
  - a. Applied learnings from university class CORE 633: Social Construction of Personal, Professional and Political Discourse in Health and Disability, for ways to engage with community and involve them in the project development.
  - b. Survey development with the SRAC through Zoom meetings.



- c. Memos written throughout.
3. Sent out surveys to all SRAC members in June 2021 via email using online link or through Canada Post which were the two preferred communication styles of members (Dillman TDM). I provided one month for members to complete the survey through the online link, with an additional week for the mail-in surveys to be returned.
4. SRAC assisted with recruitment of interview participants through their email list and social media accounts.
5. Eligible and interested participants were interviewed virtually in June and July 2021.
6. Report of survey results sent to SRAC to review in August 2021. I attended a meeting with the board of directors on September 14, 2021 to provide a project update and discuss survey results.
7. SRAC added their own action items that correlated to the responses in the survey to the report and shared it with their membership.
8. Regular contact was continued after this for updates on the SRAC and their activities, as well as providing updates on my thesis timeline, and planning a future presentation to their membership on the final research project.

#### 3.2.4 Analyzing and Interpreting the Surveys

The membership survey included 20 questions (Appendix B) and the results were shared with the SRAC board of directors. A total of 135-member email addresses were sent the survey link, and 38 responses were received through that link. Nine surveys were printed and mailed to the SRAC members who do not use email and

receive their correspondence through Canada Post. Out of the nine printed surveys, two were returned to sender due to members moving, and no other surveys were returned by mail, even though a returned stamped envelope was provided. The percentage of survey responses was not as high as anticipated (26%), but this could be due to a variety of factors. Some members do not check their emails regularly, the messages could have gone to a junk mail folder, some may have chosen to not participate, the survey may have presented challenges to some members due to cognitive or visual impairments, and there may have been errors with the email addresses themselves or the email database from the SRAC.

The results were compiled into a report through Qualtrics and shared with the SRAC board of directors. Space was left at the end of the report for the board of directors to identify action items that they wanted to work on from what they observed and interpreted in the results of the survey. At that point, I stepped away. The SRAC will continue to use the survey results as they wish. The report was shared via email with their membership in the Fall of 2021. If someone wishes to access the data from the surveys, they need to contact the SRAC board of directors, as the survey was not a formal part of data collection for this study.

### **3.3 Case Study**

Case studies in qualitative research are a methodology designed to examine a complex social phenomena within a real-world context (Crowe et al., 2011; Yin, 2018). Case study methodology is used in a variety of disciplines, often in social sciences; however, it also has a history of being used in clinical practice and research (Crowe et al., 2011). Case studies can be found in the medical setting to provide detailed critiques

and insights into specific patient clinical cases, and/or lessons to be learned (Crowe et al., 2011). For this project, a case study provides a framework to focus on, in this 'case', small group behaviour, which would be the YSS gathering together in Calgary to provide peer support to one another. It is important to note that case studies do not establish control or manipulation over behaviours (Baxter & Jack, 2008), but rather the desire is to study a contemporary event, meaning "a fluid rendition of the recent past and the present, not just the present" (Yin, 2018, p.12). The researcher in a case study has little to no control over the group, which was the case with this study. Case studies use a variety of evidence; in this project, semi-structured interviews, as well as communication with my advisory committee to get updates on the group's past and present activities, its history, and any other relevant communications. In-person group observations were not feasible due to COVID-19 restrictions and no in-person activities happened during the data collection time period.

### 3.3.1 Founders and History of Group - Setting

To understand the scope and purpose of the YSS peer support group, and to set the context for this case, it is important to understand its history. Information in this section was collected through conversations with members of the community advisory committee. The YSS peer support group officially began on October 29, 2003 in Calgary, Alberta. The first meeting was held at the Foothills Medical Centre and was attended by five YSS. The founder of the group was inspired to create a group in Calgary after they had attended a peer support group for YSS in Ontario. They quickly learned that meeting at the hospital was not suitable due to potential triggers as many participants were patients at that hospital, the parking situation was challenging at that

site, and they just wanted more of a 'community' feel. The meetings were moved to local Starbucks coffee shops instead.

Regular peer support meetings for YSS were held by the founder for approximately ten years in Calgary. The meetings included the Starbucks get togethers, and community and social activities such as going to the movies or bowling. At the ten-year mark, the founder chose to step down from leading the group and another member of the group stepped up to take over. This individual led the group from 2013-2020 (one week prior to the COVID-19 lockdowns in March 2020), and continued with organizing coffee groups for YSS, while also organizing other peer support activities that included the greater SRAC membership.

Community activities were organized twice per month and included attending Stage West and Jubilations shows, visiting comedy clubs, having lunches at the Legion, kayaking with Rocky Mountain Adaptive, and helping to organize the annual Stroke Awareness Day each June for Heart and Stroke Month, among other activities.

A new leader stepped up during COVID-19; however, meetings and social outings decreased significantly due to public health mandates related to service closures and physical/social distancing through 2020 and 2021. In 2022, there was an increase in activity including Zoom meetups and a few in-person social activities. There are plans for 2023 including the Big Bike event with the Heart and Stroke Foundation of Canada and an event for Stroke Awareness Day.

### **3.4 Methods**

The primary method of data collection for this project was semi-structured interviews with five individuals from the YSS peer support group. Interviews were

conducted over Zoom, and were approximately 30-45 minutes in length. Participants for the interviews had at least three years of engagement with the YSS peer support group, and attended at least two community-based activities with the group. This was to ensure that they had experiences to draw from for the interviews, and to minimize any recall biases that could potentially arise if asking about experiences too far into the past. Due to COVID-19 restrictions, the original plan of observing the peer support group in the community was removed from the project, as the group was not meeting together during the data gathering period of this study (in-person or virtually).

There is an argument by Braun & Clarke (2022) that sample size can be problematic in qualitative research, and that there is “no simple way to take all data related elements ... and determine the right size of data set for a particular project” (p.28). They propose not using the ‘gold standard’ of data saturation for determining the sample size, but instead use the concept of ‘information power’ (Malterud et al., 2016); and rather than sample size terminology being used, that an invitation is made to the researcher to “reflect on the information richness of their dataset and how that meshes with the aims and requirements of the study” (p. 28). A sample size of five is acceptable in a case study such as this due to the ‘information power’ (Malterud et al., 2016) that the sample holds.

Malterud et al. (2016) proposes five items to determine the ‘information power’ that a sample has on a study (Figure 1). In this case study, a) the study aim is *narrow*, the experience of YSS in the community-based peer support group in Calgary, Alberta; b) the specificity is *dense*, this type of group has not been previously described in the literature; c) CDS is used as the *applied* theory in this study; d) the quality of dialogue is

*strong* and clear, there was an established interview guide and my background knowledge of the research area; and finally, e) a thematic analysis strategy was applied to the *case*. Taking all of this into consideration, the information power is high for this study, thus indicating that a small sample size of five participants is appropriate.

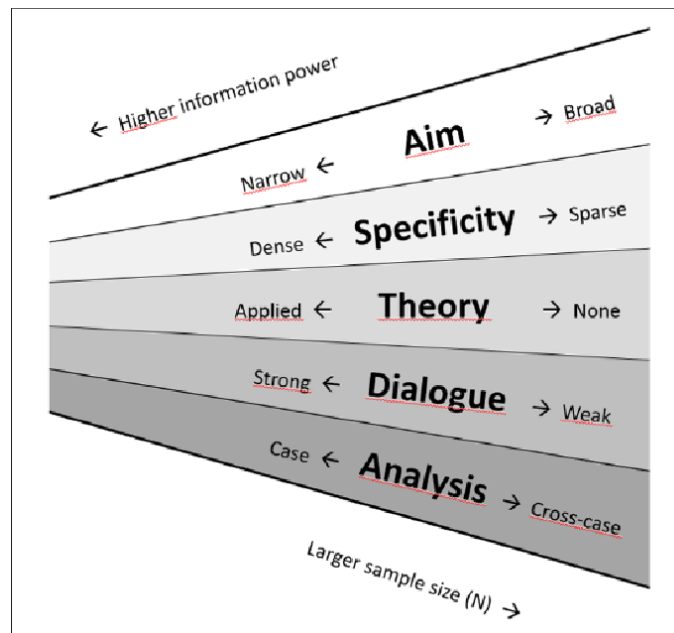


Figure 1: Information Power, Items and Dimensions (*Malterud et al., 2016, p. 1756*)

Throughout the research process, I established a memoing routine, which helped guide the process by allowing me time to be reflexive and reflective about what was happening as the project moved forward and to give the study the attention and thoughtfulness that it required (Green & Thorogood, 2018; Marlett, 2020). The research question guiding this study was: What is the experience of young stroke survivors who participate in a community-based peer support group that is solely led by the survivors themselves?

### 3.4.1 Participants for Interviews

Eligibility criteria included stroke survivors who were between 18-50 years old, who were members of the YSS peer support group, English speaking, and had participated in at least two activities in the past three years (2018-2021). People with aphasia were not excluded. Aphasia is a communication disorder that can affect “speaking, listening, reading and writing” (Armour et al., 2021, p. 1437), and it is often caused by a stroke. A speech language pathologist (SLP) was on call if any participants with aphasia required additional communication support. They were recruited in partnership with the SRAC. A pdf poster was created and emailed out to all members of the SRAC via their email list. A Facebook post was also created for the group to share on their page that had the same information as the email pdf (Appendix C). Seven members of the SRAC reached out via email and telephone, and five of the seven met eligibility criteria. Two did not meet criteria as they were over the age of 50. All eligible participants agreed to participate in a Zoom interview at a time of their convenience. All interviews were conducted in June and July 2021.

Participants have been assigned a number to distinguish them while keeping their participation anonymous (Table 2), more specifically for quotations and reference in the results section. Table 2 shows the age range of participants was between 35-50 years old (average age of 44.8) with three participants identifying as female and two identifying as male. No further demographics were collected from participants in order to maintain anonymity.

Table 2: Participant List

<b>Participant Number</b>	<b>Age</b>	<b>Gender</b>
P1	50	Male
P2	48	Female
P3	48	Female
P4	43	Female
P5	35	Male

### 3.4.2 Semi-structured Interviews

Semi-structured interviews are a method of data collection commonly used in case studies (Yin, 2018) to help to answer the why and how questions of a particular experience. For this study, mainly due to COVID-19 and health safety reasons, the interviews were conducted over Zoom. I, the interviewer, was located either at my home or at the University of Calgary to record in a secure environment. Participants were all located in their own homes for the interviews. A semi-structured interview guide was used during the interviews (Appendix D). This guide was shared with my community advisory committee for feedback during one of the SRAC board meeting updates. Some of the interview question prompts were informed from the association survey that was conducted. The five interviews ranged in time from 30 minutes to 45 minutes long.

All participants with aphasia were provided with the option of having an SLP attend the interview if they felt it would be helpful for their communication. No participants accepted the option of having an SLP join the interviews. Supported conversation strategies were used during the interviews, such as providing additional time to answer questions, speaking slowly with a natural tone and rhythm, acknowledging any communication difficulties, using yes/no to confirm understanding,



and summarizing what the participant had said (Armour et al., 2021; Kagan, 1998; Kagan et al., 2001).

### 3.4.3 Data Collection

Best practice for collecting data from semi-structured interviews is to record, with consent of the participant, and then transcribe the interviews verbatim (Green & Thorogood, 2018). Interviews were recorded through Zoom and were transcribed verbatim by me. This data was stored on a password protected laptop and a password protected OneDrive cloud through the University of Calgary as per University of Calgary policy.

Member checking is a strategy often used in qualitative research. Participants are asked to read and confirm the accuracy of their experience that they shared with the researcher (Braun & Clark, 2022). I emailed each transcript to the corresponding participant to verify the content. Member checking is a way in which I was able to emphasize the importance that the participants play in this project (Tilley, 2016). Only two out of five participants replied. One small change was made, which was a transcription error about a specific type of activity that the participant had attended.

### 3.4.4 Analyzing and Interpreting the Interview Data

Transcribed interviews were copied into NVivo12 and coded within the software program. To continue to ensure confidentiality, this software was password protected on my laptop and only participant numbers were used to identify the transcripts. This step occurred during August and September 2021. Inductive thematic analysis was performed, which meant that the process of coding was not trying to fit the data into any pre-conceived coding frame, but instead the coding was data driven. A six-step guide

was used for this recursive process (Braun & Clarke, 2006), meaning that I would go back and forth through the steps as I analyzed the data. This is a similar approach to analysis as the popular data analysis spiral (Creswell, 2018).

*Step one: Familiarize yourself with the data.* This included transcribing the interviews myself, reading and re-reading the transcripts, making notes, and memoing along the way about what I was initially seeing.

*Step two: Generating initial codes.* This was achieved by reading through and analyzing the transcripts, supported by the NVivo12 software. Repeat readings and analysis of the transcripts allowed me to generate new codes as well as add to initial codes.

*Step three: Searching for themes.* When coding, some of the codes would fall into potential themes. This was repeated for each participant transcript numerous times. Reflecting on CDS was important during this step, as well as the following two steps, as theory would direct the analysis and discussion of the data going forward.

*Step four: Reviewing themes.* I would go back and forth through the potential themes, and the data of the nodes until I felt satisfied that I did not identify anything new in the data, reaching saturation of the analysis.

*Step five: Defining and naming themes.* I confirmed the themes and the story that the analysis told. It was determined that they fit with the research question that was being asked for this project, as well as the theoretical approach being taken. Clear definitions and names for the themes and sub-themes were created during this step.

*Step six: Producing the report.* I reviewed the data for quote extracts to use for each theme in the results section of this thesis, as well as the discussion.

Birks et al. (2008) shared that “the researcher extracts meaning from the data by filtering it through their own interpretive processes” (p. 71). After taking the time to move through these six steps, I was confident that the analyzing of the data was thorough.

#### 3.4.5 Memoing

Throughout the research process, I established a memoing routine. Memoing provides an opportunity for reflexivity during a qualitative research study (Tilley, 2016). I utilized an online journaling app called Penzu, as well as notebooks, and memoed after I attended meetings with the SRAC, after I had impactful conversations with work colleagues about my research topic, after I conducted interviews with the study participants, when I was coding and analyzing the data, after committee meetings, and any other time that had me thinking more deeply about the research project. These memos helped guide the process by allowing time for me to be reflexive and reflective (Green & Thorogood, 2018; Marlett, 2020) of what happened in the research as it moved forward. Analysis was guided by the research question and my theoretical approach, namely CDS. CDS was a helpful framework for understanding shared experiences, feelings of connection with peers and a *new normal*, directly from YSS.

#### 3.4.6 Rigor

Rigor is a way within qualitative research in which one can “establish trust or confidence in the findings or results” (Thomas & Magilvy, 2011, p. 151). Credibility was established by being a reflexive researcher, by member checking the transcripts, and by sharing updates on the study with my academic committee and having discussions about my processes and results. Throughout my research project and thesis writing, I met with an established online writing group through the Writing Centre at the University

of Calgary, which included 1:1 time with writing tutors who reviewed sections of my thesis with me. In the Fall of 2021 and Winter 2022 semesters, I hosted and participated in an online writing group with students from the Community Rehabilitation and Disability Studies graduate program. I was able to discuss my findings, share my writing, check my biases, and get overall thoughtful feedback from my peers in this group. This same process was taken with an Alberta Therapeutic Recreation Association (ATRA) graduate student writing group that I organized and hosted weekly during the Winter 2023 semester. As an Indigenous graduate student, I also applied to and was accepted to two writing retreats: one in November 2021, and one in November 2022. My network of colleagues who work at the University of Calgary, and who have qualitative research experience, was also part of my rigor process, as I shared portions of my thesis with them and was able to receive deep and helpful feedback on my project. My community advisory committee could also be considered part of my rigor process, as I met with members of that committee throughout the research project to provide updates, keep open and honest communication, and to provide opportunities to receive feedback from them.

Transferability is another part of ensuring rigor (Thomas & Magilvy, 2011). This was achieved by having a clear purpose for the project, by providing a clear description of the YSS situation through the literature review, as well as a clear research methodology that aligns to answer the research question. Ultimately, I will establish that the results and conclusions from this study will enhance the field of stroke recovery, and will have done this by ensuring rigor that minimized the risk of bias and maximized the credibility of this study (Green & Thorogood, 2018; Thomas & Magilvy, 2011).

### **3.5 Ethical Engagement**

During my first meeting with the leader of the YSS group in Calgary, we discussed potential research ideas. I knew that if I was to conduct research in this area, it would need to be supported by the group. “Nothing about us, without us” comes to mind. Or a more updated term is “nothing without us” (Government of Canada, 2020). This means that YSS were included throughout the research process. I did not want to move ahead with my research unless I had the support of the group. I also met with the board of directors of the SRAC. I discussed my ideas and got feedback from them on the most meaningful ways to lead the research. Our first meeting was in February 2020 at the Carewest Vernon Fanning Centre, just before the pandemic hit. That was the last time I saw the group face to face; the remainder of our interactions were conducted via Zoom.

The Conjoint Health Research Ethics Board (CHREB) application was initially submitted on April 3, 2021. Revisions were made and Certification of Institutional Ethics Approval came through on June 9, 2021 (REB21-04112). Forms approved included recruitment materials, consent forms, confidentiality pledge, research proposal, and the interview guide.

#### **3.5.1 Consent Process**

The SRAC board of directors were considered external collaborators on this project, and thus were listed in the ethics application as such. An SLP was also listed as an external collaborator as they assisted with creating aphasia-friendly consent forms and were on call if any participants with aphasia required additional communication

support during the interviews. All external collaborators signed the approved confidentiality pledge form.

Consent forms were created using the University of Calgary templates, and three versions were created. One version was a standard form, another version was an oral consent form, and the final form was an aphasia-friendly form for any participants that requested it. All forms were approved through the CHREB. Each participant was emailed a copy of the consent forms prior to the interview. Two participants used the aphasia-friendly form, two participants preferred the oral consent form, and one used the standard form. Consent forms and confidentiality pledge forms are now stored and secured in my supervisor's office on the University of Calgary Foothills campus for the next seven years as per University of Calgary policy.

When the interviews began, I asked each participant again about consent and if they were fine to continue with the interview. If any participant had appeared distressed, fatigued, or emotional, I would have checked in with them again to see if they wished to continue with the interview. As I work with this population professionally, I was confident that I would be able to know if I needed to stop and check in with them. This did not occur during the interviews.

For the survey with the SRAC, the first slide of the Qualtrics survey included a consent statement which they had to click to continue to the survey questions. For those that received paper copies of the survey, this was on the initial letter that proceeded the survey. The Qualtrics survey had 100% consent clicked, and there were no paper surveys that were returned. CHREB approval was not required for the survey, as the

data collected was not used for the study, but instead given to the SRAC to use within their organization.

## Chapter 4.0 Results

This section contains the results of the interviews. The themes that were identified from the interviews will be outlined, including quotes from the participants. Interpretation of the themes is included in the discussion chapter that follows.

Table 3 outlines three main themes and six sub-themes that were identified in the data. I approached the data with a CDS lens and considered how the YSS navigate the world post-stroke. When I generated the themes, I purposefully and thoughtfully considered the tensions and debate between the medical model and the CDS approach to examine and understand the experiences of the participants in the peer support group.

Table 3: Themes and Sub-themes

<b>1. Feeling <i>normal</i></b>	<b>2. Connection through lived experience</b>	<b>3. Perceived benefits of attending the peer support group</b>
- What is <i>normal</i> anyways?	- Shared life and stroke experiences	- Being accepted by others
- Why does there need to be a <i>new normal</i> ?	- Mixed feelings when meeting with other survivors	- Opportunities for social interaction

### 4.1 Feeling *Normal*

Feeling *normal* was a concept mentioned specifically by participants and was determined to be an important theme in the data.

#### 4.1.1 What is *Normal* Anyway?

Participants discussed feeling *normal* as part of their experience in the community-based peer support group such as laughing together versus not being laughed at, or meeting in the community at coffee shops.



*“I think there is just huge value in feeling normal. And I think when you feel normal and content it helps you accept your situation and recover from it.” (P3)*

*“It [the peer support group] has definitely made me feel more normal, more accepting of myself.” (P3)*

*“I feel more normal. All the hidden disabilities, I guess, really make you feel very abnormal.” (P3)*

There were indirect comments about feeling *normal* throughout the interviews such as taking on a volunteer role with the in-patient stroke program (INSPIRES – Inpatient Support Program In Recovery from Stroke):

*“I was volunteering with, peer support group every other Monday.” (P2)*

Building confidence in the peer support group helped one member to step outside of their comfort zone and start to join meet up groups in the community:

*“I went to do meet up groups. ... I had the stroke symptoms; I couldn't talk as well or move as well ... but I quickly got over that.” (P5)*

#### 4.1.2 Why Does There Need to be A *New Normal*?

The term *new normal* is often used in rehabilitation to describe adjusting to living with the impairments from a stroke. No participants used this specific language, but it was implied throughout the interviews. One participant discussed the concept of planning and pacing (P3), which is often taught in the rehabilitation setting to manage post-stroke fatigue. This technique is a way to approach a *new normal* way of living.

*“In order to be successful at something I need to do a lot of pre-planning.” (P3)*

Other participants discussed that they problem solve together (P1, P4, P5) as a group, and this would also be a new technique that may now be a regular part of their life and part of their *new normal*.

Participants confirmed the value that peer support had on their lives and how including it in their lives was now a part of their *new normal*. For example, one participant shared that without peer support, “*I think I would still be struggling*” (P3). Another participant discussed that their *new normal* living with stroke was something that they have to deal with everyday (P5), and peer support helped with this adjustment.

Living within a *new normal* can take time, can require extra support, can be a challenge, and is not generally what people want to have to adjust to. This adjustment to meet certain expectations of behaviour and outcomes can be questioned within CDS, for example, should they have to adjust to these at all. This topic will be explored further in the next chapter. The participants articulated their resiliency through the interviews and their thoughts on being a young stroke survivor and adjusting to their *new normal*.

#### **4.2 Connection through Lived Experience**

The theme of connection through lived experience was a common thread in the interviews. This was not unexpected considering the literature on peer support more broadly argues that a primary benefit of peer support is building relationships and making connections (Golden et al., 2019; Heisler, 2006; Lund et al., 2018). Two sub-themes emerged. First, the positive connections that occur when YSS share their stroke experience with other young survivors such as connecting about the stroke experience itself and how the stroke interrupted family, work, and education as a younger person. Second, participants shared mixed feelings when connecting with others who have had

a stroke. The connection perhaps was being forced and was not welcomed, or the connection did not provide the hope that they were looking for. Both sub-themes are explored in detail below.

#### 4.2.1 Shared Life and Stroke Experiences

For most participants, connection through shared experience was an important part of being a member of the YSS peer support group. As participants shared:

*“Good thing I met them. Then I will know that young people do have stroke too.”*

*(P2)*

*“It was good to compare stories, and see how ... everyone recovers differently, their capabilities are different.” (P1)*

Depending on their family, social network, and community, a survivor may not have had the opportunity to meet anyone else who was a YSS. The one place that a few participants did meet other YSS was on the inpatient stroke rehabilitation unit when they were in hospital, but not all participants went through that treatment route.

The opportunity to share their stroke stories, their struggles, and their achievements has been an important part of experiencing connection with others. A participant made this known by speaking about the value of sharing life tips, and having someone listen and hold space for them:

*“It is helpful to connect with people who share a similar stroke to you. Just get*

*tips and just talk to people who understand you and can hold space for you.*

*Many, maybe not many, but people outside that don't know that I have had a*

*stroke can sometimes be impatient ... but there is none of that in the stroke*

*group. That is helpful.” (P5)*

Another example includes two YSS who met through the group. Both were single moms, had two children, and had aphasia. The connection was strong through their shared stroke experience as well as life experiences. They described this as a “*good connection*”, and that they were currently connecting “*every day*” as they were participating in the same face-to-face aphasia study. They “*exchanged phone numbers and email*” they use “*text messaging as well*”.

*“For instance, (name of YSS), who is also a stroke survivor. I was able to connect with (her) quite well. She has two kids as well. And umm, son and a daughter. And umm, she is divorced as well. Umm, ya, she has aphasia as well. And she had a right leg and arm as well compromised.” (P2)*

Aphasia was a common shared experience between the participants, specifically the two participants mentioned above. However, all five indicated that they had experienced some level of aphasia during their recovery:

*“...learning to speak again.” (P1)*

*“...voice gone.” (P2)*

*“The one thing you have to know about aphasia, ... people were happy I could communicate but they couldn’t understand that I couldn’t understand them.” (P3)*

*“Waking up. I can’t speak. I can’t read newspaper.” (P4)*

*“I wasn’t able to talk very well at the beginning when I went. It wasn’t a big deal because other people couldn’t talk very well too.” (P5)*

#### 4.2.2 Mixed Feelings when Meeting with Other Survivors

It is important to acknowledge that not all connections were positive or meaningful. Two participants shared experiences around meeting other stroke survivors

in the hospital through an inpatient peer support program. They felt that they were not ready at the time and the volunteer did not provide the hope that they desired. For example, meeting someone who was over two years post-stroke who was struggling with their communication or mobility did not instill hope in them, as they wanted to return to their pre-stroke abilities as soon as possible (P5). On a similar note, one participant mentioned having the mixed feeling of “*survivors’ guilt*”:

*“I did do so well and I know I should be dead, there’s that survivor’s guilt. So, there’s the feeling of meeting people who are younger than me that are worse than me, and therefore I shouldn’t really complain about stuff because it could be worse.” (P1)*

Mixed feelings also arose when the peer support group met and the discussion became focused on their ailments and their struggles. There was little redirection to bring it back to a supportive group conversation. One participant stated:

*“There is no therapeutic value or emotional value in having a large group of people with the same condition all complaining about how terrible things were.” (P3)*

All the study participants described positive hopeful experiences during their first peer support group meeting; however, one participant shared that someone they knew attended the group for the first time and they did not have the same experience, and the connection and hope was not there:

*“One person said that it was depressing because when they went there it was like he just saw no hope.” (P5)*

This participant did not give any further context about what specifically happened during this YSS peer support meeting, but perhaps it was just bad timing, or it was one of those meetups where the focus was more on what everyone was struggling with, rather than finding hope and support in the group.

### **4.3 Perceived Benefits of Attending the Peer Support Group**

The perceived benefits of attending the peer support group were identified as a third theme from the data. There were a few different benefits mentioned by the participants, but most were associated with being accepted by others and the opportunities for social interaction that exist because of the group.

#### **4.3.1 Being Accepted by Others**

Comfort was a word that came up multiple times in the interviews. The comfort of knowing someone understands, the comfort of being accepted, and the comfort of having someone listen were all identified as important to the participants (P2, P3, P4). Participants described their acceptance as follows:

*“It’s the one group where I feel that I can be accepted for me being me and if I use the wrong word for the coffee cup nobody cares.” (P3)*

*“I wasn’t able to talk very well at the beginning when I went. It wasn’t a big deal because other people couldn’t talk very well too.” (P5)*

*“The young survivors understand me.” (P4)*

#### **4.3.2 Opportunities for Social Interaction**

Get-togethers and texting outside of the scheduled peer support groups were identified as important for YSS recovery by some participants (P2, P3, P4).

One participant shared how important the group was to them early in their stroke recovery:

*“The only social interaction I had on a regular basis were the stroke survivor’s meetings once a month.” (P5)*

Other participants mentioned that the social interaction part of the peer support group was important due to the changes in their pre-stroke social circles:

*“Some people go away, some people stay.” (P2)*

*“Many people don’t stick around after your stroke.” (P5)*

The YSS peer support group has been using a Facebook page for many years to support social interaction and to communicate events. All five participants mentioned the use of Facebook as an important platform to keep in touch.

*“I check it [Facebook] every day.” (P1)*

*“I was also able to connect with Facebook too. There is a young stroke survivor group.” (P2)*

*“Up until last year I was very active on Facebook, and I was the one who created the young stroke survivor group and was one of the admins, but have since given that to (YSS name) and (YSS name) to look after.” (P3)*

*“...the kayaking or the canoeing, or something, on Facebook.” (P4)*

When asked about staying in touch with people that they met in the peer support group, one participant stated, *“Ya, like I have a bunch of them on Facebook, so ya, I try to” (P5).*

## Chapter 5.0 Discussion and Reflection

The theoretical lens of CDS was used to interpret the results and help highlight key discussion points and will be threaded throughout this section when discussing and reflecting on the data and results from the interviews. CDS provides a social justice lens to the data and how an acquired impairment as an adult, in this case a stroke, impacts so many aspects of day-to-day life and how the experience of peer support plays into this. There are power differentials that occur within the medical system and the community, as well as injustices within society around accessibility, employment, financial supports, and social hierarchies, which will be discussed in this chapter. This section will be organized around the themes identified in the results.

### 5.1 Feeling *Normal*

Feeling *normal* is an important topic in disability studies, and specifically with critical disability theorists, as the concept of what *normal* means is debated regularly. Many of the study participants articulated the challenges of living in an ableist society and the desire to feel *normal*, whatever that means to them or that they have been led to believe is *normal* in our society. They shared how being a member of the peer support group helped them to feel *normal*.

What is *normal*? The concept of normality is complex and should constantly be challenged. Goodley (2014) shares that “people find it difficult to define *normal* and ‘ability’ but are far more ready to have a go at categorizing ‘abnormal’ and ‘disability’” (p. xiii). This would make feeling *normal* a challenge after acquiring impairments from a stroke, as it is easy to jump to categorizing oneself as having a disability. Oliver and



Barnes (2012) also talk about this, and note that people often get excluded from everyday *normal* activities after acquiring new impairments, such as a stroke.

One of the curious components of a study with adults who have had adult-onset impairments is that many had what they likely considered a *normal* life before their stroke. It is nearly impossible not to compare yourself to who you were before your stroke, and what your *normal* was. I have experienced this myself as well after going through cancer treatments. It is really challenging to resist comparing myself and my abilities to where they were before treatment. I have observed this same thing within my own peer support groups with other cancer survivors.

Stroke survivors need medical support for a period of time after their injury, some for the rest of their lives. Due to the nature of the rehabilitation process, which includes healthcare clinicians supporting individuals with their recovery, YSS are kept in the medical system for an extended period of time, and many can become dependent on these supports. In fact, only 66% of YSS can make the shift back into the workforce two to four years post-stroke (Edwards et al., 2018). When someone with an impairment cannot meet the demands of societal expectations of high workplace productivity, they become controlled through exclusion; in other words, they become stigmatized, oppressed, and placed in a different social status due to being classified as unable to work (Oliver & Barnes, 2012). These organizational structures can then cause an individual to become socialized into the role of being disabled, which then becomes a *new normal* for the person.

### 5.1.1 Rehabilitation and Recovery

At a certain point in rehabilitation, individuals are expected to adapt to their new impairments, it “is they who must change, adapt, or learn how to cope” (Oliver & Barnes, 2012, p. 42). Lund et al. (2018) further discusses this concept of a *new normal* and that it can be seen as a ‘life project’ that “encompasses the physical, social, and emotional aspects of one’s life and involves developing a new understanding of oneself” (p.127).

The rehabilitation setting is full of “normative assumptions clustered around an able-bodied/mind ideal” (Oliver & Barnes, 2012, p. 42), including different types of assessments and scales that are used to determine progress. As I have worked in the stroke rehabilitation field for the past 12 years, I can say that I have seen some of this at play and even used it myself at times, but as my focus is mainly on community integration, I try to give those that I support the tools to challenge the societal barriers that they may come across when they return home and to their communities. One of those tools is to connect with other stroke survivors through peer support, as there is strength in numbers, and strength in building those connections.

In the medical system, rehabilitation is considered a necessary part of stroke recovery; however, it is important to recognize the additional challenges stroke survivors may face after their rehabilitation period. This includes having to adjust their lives to fit into the world, to that *new normal*. In the rehabilitation setting, we could be supporting them to understand that their impairments are a disability due to the norms and structure of society and provide them the knowledge and tools to become self-advocates and support them to build a community around them who can also act as advocates. An example of this would be connecting stroke survivors to activist groups,

such as the Disability Action Hall, which is a group of individuals in Calgary who take action on important issues that impact people with disabilities. If we provide them with this knowledge, when they come together in peer support groups, they can move forward together and challenge the norms that currently exist. We can see this at play, for example, when the YSS peer support group organizes themselves to go kayaking at a public reservoir and they demonstrate to everyone that sees them that they are not going to let any impairments or societal norms of having to be fully able bodied to participate in aquatic sports stop them. By organizing and executing peer support activities in the community, the YSS group challenges many norms that exist.

## **5.2 Connection**

The importance of connection was not an unexpected result from the data. Peer support is particularly known to support connection with others (Lund et al., 2018; Mueller et al., 2014; Wijekoon et al., 2020), as when you find someone with a similar lived experience, you can naturally be drawn to them. Finding a group where one can feel accepted after experiencing a life changing event, such as a stroke, can be incredibly impactful. Additionally, finding a group where you can interact socially, after many participants disclosed a change to their social circles and connections post-stroke, can be meaningful. When interviewing the participants, each of them had something to say about connections that they made within the peer support group. The mixed feelings results were also not unexpected as it has been minimally mentioned in the literature (Lund et al., 2012), but it can still be hard to recognize that peer support is not always well received since literature often reports solely on the positive outcomes of peer support (Adams, 2020; Crump & LaChapelle, 2022).

The interviews demonstrated that there is a time and place for this type of connection. As the participants move further along in their recovery journeys, some of them have moved on to additional ways of connecting in their communities. They have not totally left the YSS peer support group, but they have found connection through work, school, and other community meet up groups. When participants were asked if they would be reconnecting with the group once the pandemic restrictions were lifted, all five said that they would be.

#### 5.2.1 Current Peer Support Situation

The SRAC continues to be an active organization in Calgary, Alberta. They were not meeting in person during the pandemic, but instead were hosting Zoom meetings for members to connect. As mentioned earlier, this does exclude some of the membership due to comfort and skills with technology. They have started to meet in-person again, taking their time to support their members' comfort levels with face-to-face contact due to COVID-19. Connections that members have made over the years through the SRAC and YSS group might be weaker than they were as regular activities were interrupted due to the pandemic; however, as mentioned before, all participants plan on reconnecting with everyone in person when it is safe to do so. Both the general SRAC activities and the YSS activities have slowly been returning to pre-COVID levels.

By engaging with the SRAC in this study, we are supporting and validating all the work that they do and have done over the years as a grassroots organization. They are an important part of the *path to recovery* for stroke survivors and to the overall stroke community in Calgary. This type of community-based peer support group is difficult to

find in the literature, but similar groups can be found in communities across North America (American Stroke Association, n.d.; Heart & Stroke, 2019).

### 5.2.2 Aphasia

I wanted to include a section on aphasia as this was mentioned by all five of the study participants. Those who had more severe aphasia mentioned that it was meaningful when they connected with others who also had severe aphasia. I suspect if I was to interview those that attend the Calgary Aphasia Centre groups that I would hear a similar thing. Unfortunately, those with aphasia are often excluded from qualitative research studies (Luck & Rose, 2007; Wilson & Kim, 2021; Worrall, 2019); however, Simmons-Mackie & Lynch (2013) have found their involvement is increasing. I was aware of that for this study, so I made sure that I had the supports in place to include them.

We know from aphasia research that if the interview methods are appropriately designed, the communication needs of people with aphasia can be met and they can participate (Luck & Rose, 2007; Simmons-Mackie & Lynch, 2013; Wilson & Kim, 2021; Worrall, 2019). I did not initially account for this when creating my interview guide. It was within the moment, while interviewing, that I adapted and used the supported communication skills that I have experience with from my rehabilitation work with people who have aphasia. There were a few times during some of the interviews that I needed to generate ideas for the participant as they were not self-generating. For example, when asking what types of peer support group activities they had attended in the past and the participant was struggling to share anything, I suggested a few activities that I knew the group had done before, although did not know if the participant had joined in

on them. The participant then lit up and affirmed that they had indeed attended some of the activities that I suggested. “The reporting of self- versus interviewer-generated ideas is essential in a qualitative paradigm that traditionally aims for limited researcher influence, and this obviously has implications for credibility of the data” (Luck & Rose, 2007, p. 217).

Choosing to include people with aphasia in this study was important for me. People with aphasia can experience exclusion in many parts of their life and I did not want this to be one of them. As well, “the process of simply being listened to has had a positive impact on participants” (Cunningham, 1998; Ireland & Wotton, 1996; Luck & Rose, 2007). “By involving people with aphasia as informants in qualitative research, we are affirming that their opinions are valid and attainable” (Luck & Rose, 2007, p. 221).

### **5.3 Perceived Benefits**

Throughout the interviews participants mentioned a variety of benefits that they experienced. Language in CDS prioritizes inclusion and autonomy, in that the human need for autonomy is an ongoing struggle to increase participation in society of people with disabilities (Meekosha & Shuttleworth, 2009). Autonomy is not just about independent living, but also about challenging the systems of power that limit one’s individual and collective freedom (Meekosha & Shuttleworth, 2009).

#### **5.3.1 Autonomy**

After having a stroke, there may be less opportunity for someone to feel that they have autonomy. Goodley (2014) discusses oppressive practices in society towards people with disabilities, in this case, young people living with stroke, and that these practices “threaten to exclude, eradicate and neutralise those individuals, bodies, minds

and community practices that fail to fit the capitalist imperative” (p. xi). When you have these types of narratives placed on you, finding situations where you can make your own decisions is very much welcomed. Being part of a peer support group that makes their own choices around what activities to organize, participates in the planning of these activities, and keeps the nature of the group informal, supports the autonomy of the individuals choosing to participate. A shift in power can occur from the healthcare professionals to the survivor when they are actively involved in decision making for their own lives (Heisler, 2006). The YSS peer support group exists outside of the structured health system and the decisions the survivors make are in their hands.

Feeling accepted by others is something we desire as humans (Charmez, 1997). It can be challenging to disclose having a stroke to others due to the fear of not being accepted. A further argument by Charmez (1997) found that “young and middle-aged adults can find themselves ignored, rejected and stigmatized when they disclose their illness” (p. 109). This is seconded by Kessler et al. (2014), but they found in their stroke peer support study that participants felt “accepted, respected, and valued despite personal difficulties” (p. 7). This supports the theme of acceptance that was identified in the data, and the idea that meeting others they are comfortable with and who they know have had a similar experience is so important.

### 5.3.2 Future of Peer Support

We know that peer support can take many different forms, such as education-based groups, hospital-based groups, facilitation by healthcare workers or trained peer support workers, to share a few examples. They all have pros and cons, and it is important to reflect on the right place and right time for each of them. Education-based

peer support appears to work well in the hospital setting (Muller et al., 2014) and valuing trained peer support workers by including them as staff is showing some positive outcomes, yet also demonstrating the challenges of shifting the power dynamic between peers (Adams, 2020). The future of peer support for YSS in Calgary should be impacted by the findings of this project, and my hope is that these impacts include ensuring that the medical and rehabilitation community continues to support grassroots peer support groups that are run by the survivors and families themselves. There does not seem to be any risk of peer support programs disappearing, but one risk that does exist is the autonomy of a survivor-led grassroots group being overtaken by a larger organization (i.e. March of Dimes, Alberta Health Services). During this research project, the March of Dimes was conducting surveys of stroke survivors in Alberta. I am unsure of what came out of that survey; however, after contacting them, they shared that they currently only support virtual After Stroke Care programs to people in Alberta. It is hopeful that if and/or when they expand into Alberta that they will collaborate with the SRAC and recognize the work and support that they have been providing stroke survivors since the 1980's.

### 5.3.3 Leisure and Community Integration

As a recreation therapist, I could identify with the value of leisure and community integration in the experiences shared by the YSS. Social interaction was identified as a theme in the data because there was often some sort of community-based leisure activity involved such as coffee get togethers, kayaking, bowling, or comedy clubs. I did not ask specifics about the activities, such as what they liked about them or how they felt participating in the activity, as I was more focused on the peer support aspect of the



activity; however, I do not feel it can be ignored that it is a common thread in the data and a priority for the YSS peer support group.

There is strong evidence in the field of leisure studies around the benefits of social connection, specifically for well-being and quality of life (Anderson & Heyne, 2012). This sense of belonging and connection with other survivors through leisure activity could be seen throughout the interviews. By having activities in the community, the YSS peer support group is informally supporting the community integration of their group members. Community integration means that the individual lives, socializes, and participates in their own community, which is often an overarching goal of rehabilitation. Social support is also generally known to decrease loneliness and depression, and participating in peer support social activities can heighten self-esteem, increase quality of life, and improve health outcomes (Fisher et al., 2015).

#### **5.4 Implications**

Taking the time to listen to the voices of YSS has the potential to impact how stroke rehabilitation practitioners practice in the community. Ensuring that peer support is recommended to all YSS should be standard practice in the field, as outlined in stroke best practice guidelines (Cotoi et al., 2018). This study supports the importance of and impact that peer support can have on this unique group of individuals. Discussion needs to be had on each rehabilitation team about who ensures that the patient or client receives the information. Often it falls on the social worker or recreation therapist. YSS may see those therapists when they are on an inpatient rehabilitation unit, but not necessarily when they attend outpatient rehabilitation services. Establishing a process both for inpatient and outpatient rehabilitation services to connect YSS with peer

support is important, and specifically taking note of the timing of these recommendations, as some participants in this study mentioned that they were not ready when still in the hospital. Timing has also been mentioned in the best practice guidelines (Cotoi et al., 2018; Mountain et al., 2020) and is outlined in the Alberta Health Services Road to Recovery (Appendix A) as being a priority when an individual is transitioning back to the community.

In Calgary, there is an opportunity for patients to connect with the SRAC within the inpatient setting, both through the Stroke Education Group and through the Inspires peer support program, although study participants indicated they may have not been ready to hear from peers at that time. This suggests it is important for YSS to hear about peer support opportunities when they return home and are receiving outpatient or in-home rehabilitation services. If they require support to connect with these groups in the community, the recreation therapist on the team often fills that role or utilizes a therapy assistant to support the individual with connecting to the community group; however, there is no plan for when a YSS is only receiving physiotherapy and no other therapies.

I propose that peer support should be discussed with all YSS during the intake process for outpatient rehabilitation services, including early supported discharge teams. The YSS may feel more ready to engage with the peer support community at this time, and if they require any support to connect with the community groups, a referral can be made to the team recreation therapist. Although this process currently happens, it is not consistent. I hope this study will help inform a process to ensure that all YSS are provided with the opportunity to connect with the community peer support

group if they feel that it is right for them. There are currently low membership numbers in the SRAC. At the time of this writing, their membership was at 155. When there have been over 7,700 adults having strokes in the past five years in Calgary, the low numbers demonstrate there may be a gap in communicating to YSS that there is a peer support group here in the city to connect with.

I also propose that the YSS group explore peer support leadership or facilitation training for a select group of their membership, as a trained facilitator could recognize “the importance of patience and empathy, build active listening skills within the group, build good advocacy skills and be able to engage in crisis management” (Edwards et al., 2020, para. 22). This directly relates to comments made by participants around the group getting “stuck” focusing on their impairments sometimes, bringing the mood down and turning people away from the hope and support the group is known for. The March of Dimes Canada is currently developing a toolkit that the SRAC could use to train peer support facilitators. This also aligns with the YSS group looking into volunteer supports for administrative tasks such as booking event spaces and sending emails. One participant mentioned this as something that has been a challenge at times and that it might be *“good to have somebody that could coordinate [activities] for us or help with that. Like if we have an idea, they can help implement it”*. They also gave an example about an activity being planned but the address of the location was not sent out.

Finally, this study provided a new lens to explore peer support for stroke survivors. By taking a Critical Disability Studies approach, we can see how peer support has far reaching effects. We can see ways in which stroke survivors are often pathologized and reduced to their impairments, rather than being recognized as a whole

person with unique identities and experiences. This is an example of the grappling and tensions between the two paradigms of medical recovery and CDS. Although YSS still need medical interventions, we need to focus more on the social and emotional dimensions of rehabilitation, along with the social determinants of health. There is also a need for a CDS paradigm in rehabilitation and recovery to create alternative understandings of the experiences of YSS that goes beyond their diagnosis and recognizes power differences and the necessity of supporting autonomy as survivors navigate their *new normal*.

## **5.5 Limitations**

This study is not without its limitations, and it is important to reflect on and identify what they are. The timing of this research study was a limitation in itself. It was initiated pre-COVID-19, and once the pandemic hit, I was left wondering if I had to change the whole project. Instead, it was narrowed down to a more simplified project to include semi-structured interviews with no group observations. The interviews would have been conducted in-person during a non-pandemic time, but to keep everyone safe the interviews were completed over Zoom instead.

As I also experienced a recurrence of my cancer during this project, I needed to take a nine-month medical leave from completing the final thesis. This was a lot of time away from analysing, writing, and reflecting on the project. As chemotherapy can have an impact on the brain, I had to work through 'chemo brain' issues such as focus, attention, and word finding challenges.

Recall bias was also a limitation, as the participants had not joined in a peer support group for over 16 months. It can be a challenge for anyone to remember details

of activities that they may have participated in 16+ months ago, but the addition of any cognitive impairments from a stroke can make it even more challenging. In a perfect world, the participants would have been actively engaged with the group and would have had recent peer support experiences to draw from for the interviews.

In hindsight, I would have done more exploration around how to best include people with aphasia in the study. If that had been done, I could have created a more aphasia-friendly interview guide, and I would have provided those participants with the guide ahead of time so they could use their own communication strategies to prepare (Simmons-Mackie & Lynch, 2013; Wilson & Kim, 2021; Worrall, 2019).

A final limitation for this study would be the recruitment bias. Access to the recruitment materials was through email and required reading and visual skills to understand the email and poster. The other recruitment method was through Facebook, and only a small number of members use Facebook. We also know that the algorithms in social media show you certain posts in your feed and not others, which I had no control over.

## **5.6 Future Research Opportunities**

For the purposes of my thesis, I did not have the capacity to dive into details around gender, culture, or other possible intersections for the participants. This would be something to consider in future research with YSS.

A larger peer support research project in partnership with the SRAC, the Calgary Aphasia Centre, the Inspires program, and the YSS peer support group would be interesting to explore and understand the bigger picture of peer support here in Calgary. This could include surveys, interviews, observations, and involve professionals' opinions

on their experience referring to peer support and community stroke programs. This would be more of a program evaluation project that could potentially support and direct this part of the Calgary Stroke Program into the future. Peers for Progress, an international network of peer support researchers, experts, and advocates, has resources on their website to use for evaluating peer support programs that would be useful for a project such as this (Peers for Progress, n.d.).

While this research project took a CDS approach, it would be a worthwhile undertaking to look at the experiences of YSS through other critical lenses. For example, Mad studies has connections to CDS, with roots in activism, and focuses on the scholarship around the experience of psychiatric survivors, and this could support a deeper dive into some of the themes identified in this study (Menzies, LeFrancois & Reaume, 2013). Ideas around engaging in independent activity and leadership, similar to the origins of the MAP (Mental Patients Association), now called the MAP Society in Vancouver (Madness Canada, 2013), such as living with impairments from stroke and finding a sense of belonging and understanding as YSS could all be interesting threads in Mad studies. A group of YSS exploring who they are without pathologizing their impairments and understanding how that fits within the social context of our society would be unique and novel.

Another opportunity for future research could be to implement a pilot program such as the YESS or Lifestyle Redesign® program in Calgary. This could be done in partnership and/or combination between the Alberta Healthy Living Program and a community peer support group that those who have completed the program can join afterwards. The peer support could be similar to what already exists and ensure it

allows YSS to keep connected through coffee dates and activities. This part appears to be missing from the previous research, as there is no mention of a plan for the participants after they have completed the structured education-based 6–12-week peer support program.

### **5.7 Mobilization Plan and Knowledge Translation**

During this research process, I presented posters of this project at the 2020 and 2021 Alberta Therapeutic Recreation Association Symposiums. In addition, I am scheduled to present a poster at the O'Brien Institute of Public Health Interdisciplinary Student Research Showcase on April 27, 2023. I presented, and was a finalist, at the 180 Pitch Competition in November 2021 which was hosted by the Canadian Partnership for Stroke Recovery's National Trainee Association. I was accepted to present at the Canadian Therapeutic Recreation Association (CTRA) conference in May 2022 for a 60-minute research presentation; however, due to my cancer treatment I had to cancel that presentation. I have been accepted and will be presenting at the CTRA conference in May 2023 instead. For this presentation, I am aiming to have one of the study participants co-present with me. Finally, I will be presenting to the SRAC and their membership in the Spring of 2023 when my thesis is completed.

I intend to apply to present a poster of this research at future conferences that align with the project such as the World Stroke Congress in October 2023 in Toronto and/or the World Congress for Neurorehabilitation in May 2024 in Vancouver. Moreover, I plan on exploring publication options within a stroke journal, a disability studies journal, and/or a recreation therapy journal. As previously mentioned, if the SRAC would like me

to assist in sharing survey results with their members or other stakeholders, I will be supporting that process as well.

The SRAC was collaborative, welcoming, and a pleasure to work with. The statement, “each person learns from others and grows in his or her own confidence and capacity” (Marlett, 2010) feels appropriate here, as the community engagement portion of this project was a great learning experience for me. My hope is that the SRAC will reach out to myself or the University of Calgary if they are interested in collaborating in the future.

## **5.8 Conclusion**

Taking the time to explore the experiences of YSS in a community-based peer support group has been an honour and a pleasure. Several conclusions can be made based on the results of this study. First, YSS in Calgary are experiencing connection through shared lived experience of being young and having a stroke. Second, social interaction and community involvement with people you trust creates benefits for individuals and the greater community. Third, there are ongoing challenges with adults who have acquired impairments through a stroke fitting into society’s concept of *normal*; however, being part of a community-based peer support group can be a safe place to help navigate these challenges. Finally, it is important for agencies to recognize the need for supports, such as facilitator training or administrative assistance, to help YSS thrive in the community. The results of this study showcase the unique experiences of YSS in a community-based peer support group. When someone chooses to participate in this group, they are making a choice to not only find support for themselves, but also provide support to others who also live a similar experience.



As more Canadians are living with stroke and more young people are being impacted by this health issue, it is important that we find ways to connect them with others who have a shared lived experience so that they have ongoing support as they continue to live in a world that is not fully accessible or inclusive. As healthcare providers and researchers, we need to be strong allies of YSS and advocate for their continued care within the healthcare system, as well as in their community-based, grassroots peer support groups.

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# Appendix A

## Alberta Health Services: The Road to Recovery After Stroke





## Appendix B

Stroke Recovery Association of Calgary membership survey questions:

1. Thank you for taking the time to complete this survey today. Just a reminder that this will take approximately 10-15 minutes and that if you do not finish it, you can come back to it within one week. You are also able to skip any questions that you do not wish to answer.

This survey is voluntary and at any time if you want to stop you can just close the survey page.

Do you consent to move forward to the survey questions?

- Yes, I consent
- No, I do not consent

2. Are you a:

- Stroke survivor
- Caregiver
- Other

3. What year did you have your stroke?

- Drop down arrow (1980 – 2021)

4. When did you first hear about the Stroke Recovery Association of Calgary?

- Drop down arrow (1980 – 2021)

5. Do you have any comments about the annual \$20 membership fees? (too much, too little, worth it for the benefits, not worth it for the benefits, ...)

- Open-ended question

6. Which activities have you participated in with the Stroke Recovery Association of Calgary? (please select all that apply)

- Monthly meetings
- Guest speakers
- Monthly lunches (at Denny's or Carriage House Inn)
- Recreation activities (golfing, yoga, sailing, picnics, bowling, hiking, biking, etc.)
- Stroke Awareness Day
- Annual Summer BBQ
- Annual Christmas Party

7. What have you liked MOST about being a member of the Stroke Recovery Association of Calgary? (please select all that apply)

- Monthly meetings
- Guest speakers
- Parties (Christmas, Summer BBQ)
- Monthly lunches
- Socializing with other stroke survivors
- Knowledge and resource sharing

8. Do you have any other comments about what you have liked MOST about being a member of the Stroke Recovery Association of Calgary?

- Open-ended

9. What have you liked LEAST about being a member of the Stroke Recovery Association of Calgary?

- Open-ended

10. What is your preferred time of day for activities? (select all that apply)

- Mornings
- Afternoons
- Evenings
- No preference

11. What is your preferred location for activities? (select all that apply)

- Good Companions Club (Killarney)
- Horton Road Legion
- Denny's on McKnight
- Carriage House Inn
- No preference

12. Do you have any other comments about times, days, locations or accessibility of activities?

- Open-ended

13. What would you like to SEE MORE OF from the Stroke Recovery Association of Calgary?

- Educational events
- Recreation events
- Parties
- Lunches

14. Do you have any other comments about what you would like to SEE MORE OF from the Stroke Recovery Association of Calgary?

- Open-ended

15. Are you interested in joining virtual meetings or activities? (for example, using Zoom)

- Yes
- No
- Unsure

16. Do you have any other comments about virtual meetings or activities?

- Open-ended

17. Would you be interested in taking part in stroke or other health related research projects?

- Yes
- No
- Unsure

18. Have you been on the Stroke Recovery Association of Calgary website?

([www.sracalgary.com](http://www.sracalgary.com))

- Yes
- No
- Unsure

18A. Did you find the website easy to navigate?

- Yes
- No
- It could be more user friendly
- Unsure

18B. What else would you like to see on the website?

- Open-ended

19. What is your preferred method of communication from the Stroke Recovery Association of Calgary?

- Email
- Regular postal mail
- Telephone
- In-person /word-of-mouth

19.A. Have you been satisfied with the level of communication that you have received from the Stroke Recovery Association of Calgary?

- Yes
- No

19.B. If no, what do you feel could be done to improve communication?

- Open-ended

20. Would you be interested in VOLUNTEERING with the Stroke Recovery Association of Calgary? (This survey is anonymous; no contact will be made with you if you answer yes. For further information on volunteering visit [www.sracalgary.com](http://www.sracalgary.com) and click the 'Get involved' tab.)

- Yes
- No
- Unsure

21. Thank you again for taking the time to complete this survey. If you have any further questions, they can be directed to [gary@sracalgary.com](mailto:gary@sracalgary.com).

## Appendix C

### Recruitment poster (email):



 **UNIVERSITY OF  
CALGARY**

**EXPERIENCE OF YOUNG STROKE  
SURVIVORS IN A COMMUNITY-BASED  
PEER SUPPORT GROUP**

A study at the University of Calgary is exploring the experience of young stroke survivors in a community-based peer support group. We hope this study will continue to impact stroke rehabilitation best practice of recommending peer support groups for recovery of young stroke survivors.

Are you:

- a young stroke survivor between the ages of 18-50?
- a member of the Stroke Recovery Association of Calgary's Young Stroke Survivor (YSS) group? And have participated in at least two YSS activities in the past three years?

If so:

- would you like to give an interview about your experience? You will be compensated for your time.

**If you are interested in participating,  
please contact  
Tiffany Morin at: 403-596-2282 or  
tdmorin@ucalgary.ca**

This study has been approved by the University of Calgary  
Conjoint Health Research Ethics Board.  
Ethics ID: REB21-0412  
Principal Investigator: Katrina Milaney, PhD

**Facebook post:**



**EXPERIENCE OF YOUNG STROKE SURVIVORS IN A COMMUNITY-BASED PEER SUPPORT GROUP**

Are you:

- a young stroke survivor between the ages of 18-50?
- a member of the Stroke Recovery Association of Calgary's Young Stroke Survivor (YSS) group? And have participated in at least two YSS activities in the past three years?

If so:

- would you like to give an interview about your experience? You will be compensated for your time.



**If you are interested in participating, please contact  
Tiffany Morin at: 403-596-2282 or [tdmorin@ucalgary.ca](mailto:tdmorin@ucalgary.ca)**

This study has been approved by the University of Calgary Conjoint Health Research Ethics Board. Ethics ID: REB21-0412, Principal Investigator: Katrina Milaney, PhD

## Appendix D

### Interview Guide

**Opening statement:** Thank you again for agreeing to be interviewed today. We are going to discuss your experience as a young stroke survivor engaging in a community-based peer support group. Just as a reminder, if at any time you need a break, please let me know. If you want to skip a question, or stop the interview, let me know.

Review the general study information again with participant and provide an opportunity for them to ask any questions prior to starting interview.

Are you comfortable sharing your stroke story with me today?

- Prompts: Type of stroke? What season was it? Date? Time of day? Who was with you? Where were you?

Let's talk about being a stroke survivor. What does that mean to you?

- Prompts: How does it impact your personal identity? Your family? Your friends? Your social life? Your professional life?

What is like being a young stroke survivor in Calgary?

- Prompts: How long have you lived here? General social connections? Community connections?

At what point in your recovery did you hear about the Young Stroke Survivor group here in Calgary?

- Prompts: Who was your first contact? What was your first activity?

How did meeting other young stroke survivors make you feel?

- Provide extra time to consider the question. Tell me more. Go on. What happened then.



What kind of impact has being a member of the Young Stroke Survivor group made on your life? Your family's life? (partner, children, etc.)

- Prompts: (do not imply positive or negative here, let the participant describe this as best they can) Time commitment? Priority? Social connections?

What else would you like to tell me about participating in the Young Stroke Survivor group?

- Prompts: Final thoughts? When the group can safely meet in person again, will you be joining? Anything else?

Do you have a preferred pseudonym that you'd like to use in the transcripts of this interview?

When I am writing the final research project report (thesis) and I have any questions for you regarding any quotes or to clarify anything, may I contact you?