

PHYSICAL ACTIVITY MAINTENANCE AND ADULTS WITH SPINAL CORD INJURY

**Exploring Physical Activity Maintenance Among Adults with Spinal Cord Injury**

By

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### Abstract

**Background:** Approximately 12% of adults with spinal cord injury (SCI) meet physical activity (PA) recommendations. There is limited research understanding the factors that enable adults with SCI to maintain their PA participation. The purpose of this study was to qualitatively explore how and why adults with SCI maintain PA. **Methods:** Using a multiple case study design, four adults (20-44 yrs.) living with a SCI who maintained PA for one or more years post rehabilitation consented to participate in this study. The adults with SCI participated in two interviews and submitted a reflection log and pictures. The adults who facilitated participants PA were also interviewed. A cross-case analysis was used to analyze the cases to identify the how and why of PA maintenance in this population. **Results:** The results of this study suggest specific reasons as to why adults with SCI maintain their PA participation including, minimizing health risk, maintaining strength for transfers and wheeling, and the inclusive environment of parasport. Participants reported the strategies they engage in to maintain PA included prioritization, time management, accountability by teammates or peers, and finding enjoyable activities.

**Conclusion:** The results from this multiple case-study provides novel insight and direction to continue to explore the promotion of physical activity maintenance in the adult SCI population. The findings of this study revealed that the awareness and direct connection participants made between their improved health and SCI self-care (ease in transfers and mobility) and physical activity strongly supported their physical activity maintenance. The results also align with existing frameworks including experiential aspects of participation, or quality participation among the disability community. Future research is warranted in understanding the the influence physical activity prior to SCI may have towards physical activity maintenance and increasing adults with SCI connection of their physical activity maintenance with on-going health benefits.

## Résumé

**Contexte:** Environ 12 % des adultes ayant une lésion médullaire (LM) respectent les recommandations en matière d'activité physique (AP). Il existe peu de recherches sur les facteurs qui permettent les adultes ayant une LM de maintenir leur participation à l'AP. Le but de cette étude était d'explorer qualitativement comment et pourquoi les adultes atteints de LM maintiennent leur AP. **Méthodes:** En utilisant une méthodologie d'étude de cas multiples, quatre adultes (20-44 ans) ayant une LM qui ont maintenu leur AP pendant une ou plusieurs années ont consenties à participer à cette étude. Les adultes ayant une LM ont participé à deux entrevues et ont soumis un journal de réflexion et des photos. Les adultes qui ont facilité l'AP des participants ont également été interviewés. Une analyse de cas croisés a été utilisée pour analyser les cas afin d'identifier le comment et le pourquoi du maintien de l'AP dans cette population. **Résultats:** Les résultats de cette étude suggèrent des raisons spécifiques pour lesquelles les adultes atteints d'une LM maintiennent leur participation à l'AP, y compris la minimisation des risques pour la santé, le maintien de la force pour les transferts et les déplacements, et l'environnement inclusif du parasport. Les participants ont indiqué que les stratégies qu'ils utilisent pour maintenir leur AP comprennent l'établissement de priorités, la gestion du temps, la responsabilisation par les coéquipiers ou les pairs et identifier des activités amusantes. **Conclusion:** Les résultats de cette étude de cas multiples fournissent un nouvel aperçu et une orientation pour continuer à explorer la promotion du maintien de l'activité physique dans la population des adulte ayant un LM. Les résultats de cette étude ont révélé que la prise de conscience et le lien direct que les participants ont fait entre l'amélioration de leur santé et leur autonomie (facilité des transferts et de la mobilité) et l'activité physique ont soutenu leur maintien de l'AP. Ces résultats ont aussi un lien avec des modèles courantes tel que les aspects expérientiels de la participation au sein de la

communauté des personnes handicapées. Les recherches futures sont justifiées pour comprendre l'influence que l'activité physique avant une personne ait une LM peut avoir sur le maintien de l'activité physique, en plus de trouver des stratégies pour augmenter le lien entre les adultes atteints d'une LM font entre le maintien de leur AP et les avantages pour la santé.



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### **Contribution of Authors**

T. M. Liska is the primary author of this study and carried out the collection of data, writing, and preparation of the thesis.

Dr. S.N. Sweet, Associate Professor, Department of Kinesiology and Physical Education, McGill University, the candidate's supervisor was actively involved in every step and decision made regarding the research study and the completion of this thesis. In addition, he was the critical friend for data analysis to ensure the comprehensiveness of this thesis.

H. Flaro, Executive Director of Ability New Brunswick, was a contributing author for the manuscript and involved in the data analysis and interpretation of the results of this study. In addition, she was a critical friend, providing input on the interpretation of results.

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## **Chapter 1: Introduction**

A spinal cord injury (SCI) is defined as damage to the spinal cord resulting in complete or incomplete sensory, motor, and autonomic dysfunction to affected nerves within the body. The damage to the spinal cord, resulting in a SCI, can be caused by a traumatic or non-traumatic event (Singh et al., 2014). Traumatic SCIs occur when an external force, such as a motor vehicle injury, fall, sports-related injury or violence, physically impacts the spinal cord resulting in acute damage (Ahuja et al., 2017). Non-traumatic SCIs are caused by an acute or chronic disease that inflicts damage to the spinal cord (Ahuja et al., 2017). Examples of medical conditions that provoke non-traumatic SCIs include, but are not limited to, vertebral spondylosis, tumor compression, vascular ischemia, and neuronal motor disease (Ahuja et al., 2017; Guilcher et al., 2010). Individuals who experience a non-traumatic SCI typically have a shorter duration of rehabilitation in comparison to individuals with a traumatic SCI, as well as a lower prevalence of secondary health condition such as, neuropathic pain, spasticity, urinary tract infections, joint contractures, shoulder problems, and bowel incontinence (McCammon & Ethans, 2011).

In the USA, there is an average of 40 per million new cases of SCIs annually, and 37 per million new cases in Canada. Evidence indicates that there has been an increase in the median age of SCI among Canadian's from 34.5 years of age to 41.5 years of age (Lenehan et al., 2012; Noonan et al., 2012). Moreover, the prevalence of SCI is three to four times higher among men (DeVivo, 2012; Singh et al., 2014). Pickett et al. (2003) reports, however, that over a five-year period the rate of SCI among men have decreased whereas the rates of SCI among women have remained stable.

Motor vehicle accidents are the leading cause of SCI in Canada and the USA contributing to approximately 50%-60% of SCI (DeVivo, 2012; Noonan et al., 2012; Noreau et al., 2014).

Canadian literature indicates that over the last decade, there has been a decrease in SCI caused by motor vehicle accidents accounting for approximately 45% of all SCIs (Lenehan et al., 2012). Despite this decline, motor vehicle accidents remain the leading cause of SCI among patients under the age of 55, with the incidence of motor vehicle injuries for males being higher than for females, irrespective of age (Lenehan et al., 2012; Pickett et al., 2003). However, falls are reported to be the leading cause of SCI in the beyond the age of 55 (Lenehan et al., 2012; Noreau et al., 2014; Pickett et al., 2003). There has also been a decline in the severity of injuries over the last 30 years, and increase in the mean age of injury from approximately 28 years to approximately 37 years from the 1970's to 2008 (DeVivo, 2012; Noreau et al., 2014).

Age of injury remain highest for individuals in their late teens and early twenties, with peak occurrences of SCI in Canada occurring between the ages of 15 and 35, and decline thereafter (DeVivo, 2012; Noreau et al., 2014). Incident rates of SCIs are lowest amongst the pediatric age group, notably children ages 10 and under (DeVivo, 2012; Lenehan et al., 2012; Pickett et al., 2003). Literature has noted that the age in which a SCI occurs in an individual is important. The older an individual is at the time of injury, there is an increase frequency in the occurrences of complications, duration of rehabilitation, and risk of mortality (DeVivo, 2012; McCammon & Ethans, 2011).

Despite the increased risk of mortality with age, adults with SCI report that their overall health is vastly the same at five years and 30 years post injury, with the total percent of adults with SCI who have been re-hospitalize at 30 years post injury being lower than those re-hospitalized at five years post injury (DeVivo, 2012). Additionally, studies have shown that health outcomes are as good, if not stronger 20 to 30 years post injury than during the first few years post injury (DeVivo, 2012).

A SCI leads to lifestyle changes including the use of a mobility aid such as a walker, crutches, or wheelchair and changes to personal care routines and treatment for pressure injuries. Individuals with SCI may also face accessibility barriers within the physical environment, impeding individuals with SCI with the ability to engage within their community (Best et al., 2017; Mascarinas & Blauwet, 2018; Sweet et al., 2012; Todd & Martin Ginis, 2019). One of several daily living activities that has been shown to decline when a person is diagnosed with a SCI is engagement in physical activity. Physical activity is defined as any bodily movement produced by the skeletal muscles that increases energy expenditure and heart rate (Caspersen et al., 1985). Considering the broad definition of physical activity, the operational definition of physical activity in the context of this study will be synonymous with leisure-time physical activity (LTPA). Leisure-time physical activity is a subset of physical activity, defined as physical activity that an individual chooses to do during their free time, including sport, wheeling for exercise, and strength-training activities (Martin Ginis et al., 2010). Blauwet (2019) reports that because of comorbidities related to SCI such as dyslipidemia, abnormal glycemic control, chronic inflammation, and immobility, adults with SCI are less likely to choose to engage in physical activity during their free time (i.e., LTPA). As a result, adults with SCI report significant decrease in their physical activity participation, and greater physically deconditioned, than the general population, including other physically disability populations (Martin Ginis et al., 2018; Rocchi et al., 2017).

Rimmer (2010) expressed that the breadth and scope of physical activity and exercise within disability populations literature has been limited, or in some cases absent. With a call for evidence-based practices to further understand possible implications for engagement in physical activity amongst disability populations, there has been a growth within medical rehabilitation

research in investigating evidence-based physical activity interventions for disability populations (Rimmer, 2010). This growth has provided an increased understanding within the SCI literature pertaining to physical activity participation, intervention, and outcomes towards adults with SCI.

Evidence indicates that approximately 50% of adults with SCI receive zero minutes of physical activity, whereas approximately 12% of adults with SCI meet the recommendations in the *Spinal Cord Injury Specific Physical Activity Guidelines* (Best et al., 2017; Sweet, et al, 2012). However, to date, much research has focused initiation and short-term outcomes of adult with SCI to engage in physical activity, and not towards the behaviours and actions associated with the maintenance of physical activity participation (Conner & Norman, 2017). Thus, there is limited evidence that reports as to how and why some adults with spinal cord injury are able to maintain regular physical activity participation (Best et al., 2017; Sweet et al., 2012).

Researchers and health care providers express that attention cannot solely be given to the 50% of the SCI population that are inactive.

### **1.1 Purpose of the Study**

Considering an absence of information regarding maintenance to physical activity amongst adults with SCI, the examination of physical activity maintenance in the adult SCI population should be further explored. Therefore, the purpose of the research project was to gain further understanding of adults with SCI who maintain physical activity participation. The research question of this study is *how* and *why* do adults with SCI maintain their participation to physical activity?

## **Chapter 2: Literature Review**

### **2.1 Physical Activity and Spinal Cord Injury**

Adults with SCI who engage in regular physical activity experience improvements in their physical fitness including increases in cardiovascular endurance, muscle mass, and muscular strength (Blauwet, 2019; van der Scheer et al., 2017). Additionally, from an intrapersonal perspective, individuals with SCI report experiencing improvements in their physical and psychosocial well-being from continuous participation in physical activity (Carroll et al., 2014; Latimer et al., 2004; Tomasone et al., 2013). The noticeable improvements towards quality of life and one's personal health, resultant from physical activity participation, has been associated with a person's drive to elevate the negative associations of SCI and improve their mental functioning, physical capability and functional ability, and social relationship (Nightingale et al., 2018).

Specific factors as to why adults with SCI choose to engage in physical activity include experiencing feelings of enjoyment, improvement in their fitness, engaging in competition, socialization, and maintaining their physical and mental health (Kerstin et al., 2006). Additionally, adults with SCI report interpersonal factors for engaging in physical activity including gaining independence, establishing a self-image of being active and a role model to others, being a part of a social network, becoming competitive, and experiencing improvement in their health and physical appearance (Kerstin et al., 2006). The rise of research and awareness of physical activity within the adult SCI population has led to an increase in evidence suggesting that there are adults with SCI who adopt a physically active lifestyle, despite the barriers faced when attempting to engage in physical activity (Kerstin et al., 2006).

Initial introduction to physical activity post-injury often occurs during rehabilitation. Physical activity opportunities that exist within SCI rehabilitation, including structured gym session, group exercise, and recreational sports organized by other health professionals or supported by members of a local parasports club or organization (Williams et al., 2018). Best et al. (2017), however, express that physical activity participation for adults with SCI should go beyond activity within a rehabilitation setting. Physical activity and SCI literature illustrates that adult with SCI experience improvements in their physical and psychosocial well-being from participating in community based physical activity, providing enhancements to individuals on-going physical activity participation (Best et al., 2017).

The combination of introducing physical activity programs within SCI rehabilitation, and the increased reach and efficacy of community-based physical activity programs has contributed to physical activity promotion among the adult SCI community. Moreover, the increased opportunities for physical activity within rehabilitation, and more so multidisciplinary partnership at the community level, have advanced how adults with SCI can access, and subsequently maintain, physical activity participation (Martin Ginis et al., 2012a). Implementation of evidence-based physical activity from researchers to promote program efficacy and adoption, and community partners who have established program to facilitate communication and implementation has allowed for knowledge mobilization and successful reach of community-based physical activity programs for adults with SCI (Martin Ginis et al., 2012a).

When community-based physical activity is accessible for adults with SCI, there is an increase in intentions for engagement (Kerstin et al., 2006). Shields et al. (2019) emphasized community-based mentorship in coaching, providing support, and encouragement having



positive associations for adults with SCI engagement in physical activity. Community-based programs and interventions that provide physical activity, nutrition, and lifestyle management education have been shown to improve physical activity self-efficacy and self-reported health for adults with SCI and decrease the number or severity of secondary chronic health conditions related SCI and sedentary lifestyle (Nightingale et al., 2018).

Despite the introduction of physical activity in rehabilitation settings and opportunity for engagement in accessible, community-based physical activity programs, the current literature indicates that the adult SCI population engagement in physical activity remains low (Martin Ginis et al., 2010). The low physical activity engagement within this population has profound impacts on the daily functioning and living among adults with SCI, as inactivity leads to physical deconditioning and a decline in physical capacity (Martin Ginis et al., 2010). There is an increased risk of occurrence of multi-morbidities that arise from complications and chronic diseases associated with an SCI and corresponding sedentary lifestyle. Increase occurrences of physical decondition and chronic disease has contributed to an increase in hospital re-admission and health care utilization by individuals with SCI (Martin Ginis et al., 2010; Noonan et al., 2014). Gibbs et al. (2021) highlights these concerns, identifying that there are inconsistencies in interventions aimed towards improving health and mitigating the risk of associated multi-morbidities in adults with SCI. Gibbs et al. (2021) reported that few studies provided sufficient evidence in the reduction of chronic disease risk among active, community dwelling adults with SCI because of short-term follow-ups in current interventions. The inconsistent understanding of reducing multi-morbidities among community dwelling adults presents a barrier in communicating the associated health benefits of physical activity engagement to adults with SCI.

The barrier of communicating these health benefits contributes to preventing attempts to engage in physical activity upon discharge from rehabilitation.

In addition to physical health complications, adults with SCI report experiencing an increase level of fatigue, discouraging their participation in physical activity, as well as increased feelings depression, anxiety, and low self-efficacy towards physical activity participation (Nightingale et al., 2018). Such feelings are stemmed from the increased physical, psychological, and environmental challenges, or barriers faced by adults with SCI upon discharge from rehabilitation centers and attempting to engage in physical activity within community settings (Best et al., 2017; Bonelle et al., 2021; van den Berg-Emons et al., 2008).

## **2. 2 Spinal Cord Injury Physical Activity Barriers**

Although physical activity literature indicates that a person's participation in physical activity can provide multiple health benefits, and reduce the risk of some chronic diseases, physical activity participation with the adult SCI population remains low (Martin Ginis et al., 2010; Tremblay et al., 2011). The decrease or cessation of daily physical activity amongst adults with SCI often occurs at the time of diagnosis and rehabilitation (Best et al., 2017; Sweet et al., 2012; van den Berg-Emons et al., 2008). Evidence indicates that upon discharge from rehabilitation, and as age and years post injury begin to increase, adults with SCI choosing to participate in physical activity decreases (Martin Ginis et al., 2010; Rocchi et al., 2017). Additionally, women with SCI, regardless of diagnosis, are less physically active then men. Regardless of these individual factors, the cessation of physical activity among all adults with SCI remains exceptionally high in comparison to the healthy adult population (Martin Ginis et al., 2010; Martin Ginis et al., 2016).

Persons requiring a power wheelchair versus a manual wheelchair or mobility aid, and diagnosed with tetraplegia, or most severe SCI, versus paraplegia have been reported to be significantly less physically active (Martin Ginis et al., 2010). Person with SCI who had increased mobility and functional status, corresponding to lower levels of injury or paraplegia, as well as motor-incomplete injuries, had more frequent engagement in weekly physical activity participation compared to individuals with motor-complete tetraplegia (Manns et al., 1999; Martin Ginis et al., 2010). Given the difference in physical functioning in people with complete tetraplegia, and need for personal assistance and restriction to use of adapted exercise equipment during workouts, it is understandable of the increase reports of more frequent barriers and higher avoidance to physical activity participation (Martin Ginis et al., 2010).

Additionally, given the difference of impairment and increased functional status among adults with SCI who can self-propel a wheelchair, those who use a manual wheelchair report more physical activity engagement than power wheelchair users. Interestingly, those who use manual wheelchairs also report increased physical activity participation than individuals with SCI who use gait aids, for example forearm crutches or walker. (Lawrason et al., 2020; Martin Ginis et al., 2010). Seven to 10 percent of ambulators with SCI participate in sports, whereas 25-28% of adults with SCI who use manual wheelchairs report being involved in sport (Lawrason et al., 2020). Although it may be suspected that someone who has increased mobility and can walk would report increased engagement in physical activity, it is likely that greater energy demands with gait aids than a manual wheelchair may impact the individual's choice to further engage in physical activity (Lawrason et al., 2020; Martin Ginis et al., 2010).

Factors that result in decreased participation to physical activity also include increased number of unique physical and psychosocial barriers resulting from an SCI (Kerstin et al., 2006;

Martin Ginis et al., 2018; Todd & Martin Ginis, 2019). Physical barriers to physical activity are reported to include a lack of accessible transportation, inadequate accessibility in facilities, commuting long-distances to accessible facilities, as well as poor outdoor climate and environmental terrain (Blauwet, 2019; Kerstin et al., 2006). Psychosocially, decrease of self-efficacy or motivation, decreased enjoyment or beliefs towards physical activity, unsafe neighborhoods, and insufficient support from others have been reported as barriers to physical activity engagement (Kerstin et al., 2006). Positive and adequate social support is considered an influential aspect for a person with a physical disability to be physically active, including adults with SCI. The absence of knowledgeable trainers in adaptive physical activity, negative attitudes towards persons with disabilities, inaccessible infrastructures, and low confidence, however, have been recorded as preventing physical activity participation among adults with physical disability and SCI (Bonnell et al., 2021; Kerstin et al., 2006).

Additional barriers to physical activity include lack of suitable, or adaptive, physical activity programming and settings (i.e., fitness centers) within the community (Bonnell et al., 2021). The lack of community-based physical activity programs removes opportunities for people with SCI to engage within their community and meaningful activity, decreasing opportunities for socialization, and increasing feelings of isolation (Martin Ginis et al., 2018). The compounding effects of the physical, psychosocial, and environmental barriers contributing to low physical activity rates are concerning in the SCI population given the increase occurrences of chronic diseases and decrease reports of personal well-being (Blauwet, 2019; Noonan et al., 2014).

With the drive to improve quality of life and health, but the difficulty in participation because of frequent encounters to barriers related to SCI, difficulty in adhering to physical

activity participation is a common among adults with SCI (Gorgey, 2014). Given the positive outcomes associated with on-going physical activity participation, evidence-based physical activity guidelines have been established to assist researchers and health care professionals in prescribing, evaluating, and promoting physical activity within the SCI population.

### **2.3 Scientific Exercise Guidelines for Adults with Spinal Cord Injury**

Evidence-based physical activity guidelines were established for health care providers as a guide for prescribing exercise and promoting suitable physical activity engagement for the adults SCI population. *Scientific Exercise Guidelines for Adults with Spinal Cord Injury* recommend that, for fitness benefits, adult with SCI engage in a minimum of 20 minutes of moderate to vigorous cardiovascular exercises twice a week, in addition to three set of strength-training exercises for each functional major muscle group three times a week (Martin Ginis et al., 2018). Additionally, for cardio-metabolic health specifically, the *Scientific Exercise Guidelines for Adults with Spinal Cord Injury* recommend individuals engage in 30 minutes of moderate to vigorous aerobic exercises three time a week (Martin Ginis et al., 2018).

The two separate guidelines are recommended by the developers of the scientific exercise guidelines in effort to maintain the empirical evidence associated with each recommendation (Martin Ginis et al., 2018). The panel of developers reasoned that combining the limited evidence related to fitness and cardio-metabolic health outcomes for adults with SCI into a single recommendation would bring down the strength of the guideline in improving fitness outcomes (Martin Ginis et al., 2018). Therefore, the two distinct recommendations remain separate to serve as appropriate guidance dependent on the needs of the adult with SCI utilizing the guidelines (Martin Ginis et al., 2018).

With the development of the *Scientific Exercise Guidelines for Adults with Spinal Cord Injury*, recent SCI and physical activity literature concur with previous evidence that adults with SCI are by-in-large inactive. Evidence indicates that approximately 50% of adults with SCI engage in zero minutes of physical activity, whereas approximately 12% of adults with SCI met or exceed the recommendations within the fitness guidelines (Martin Ginis et al., 2010; Rocchi et al., 2017; Sweet et al., 2012). Considering that nearly half the SCI population do not engage in physical activity, but engagement in physical activity is positively associated with physical and psychosocial well-being, researchers have increased their focus on areas of behavior change, motivation strategies, as well as evidence-based community programming (Latimer et al., 2004; Nightingale et al., 2018; Rocchi et al., 2017).

Despite the literature stating the benefit of physical activity programming for on-going participation and adherence to physical activity, the longevity of such positive strategies and community-based programming initiatives has yet to be examined (Best et al., 2017). To date, much research has focused initiation and short-term outcomes of adult with SCI to engage in physical activity, and not towards the behaviours and actions associated with the maintenance of physical activity participation (Conner & Norman, 2017). There is limited evidence that reports as to how and why the reported 12% of the SCI population continue meet the *Scientific Exercise Guidelines for Adults with Spinal Cord Injury* (Best et al., 2017; Rocchi et al., 2017). There is a greater need in understanding adults with SCI who continue to meet the recommendations within the *Scientific Exercise Guidelines for Adults with Spinal Cord Injury* and maintain their physical activity participation<sup>1</sup> (Conner & Norman, 2017).

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<sup>1</sup>Moving forward, reference to physical activity maintenance among adults with SCI will be based on the sustained accumulation of the recommendations listed in the *Spinal Cord Injury Specific Exercise Guidelines*.

## 2.4 Prevalence of Physical Activity Maintenance

Current evidence indicates that the majority of the adult SCI population have not been successful in maintaining their physical activity participation (van den Berg-Emons et al., 2008). There is a low prevalence of adults with SCI who continue to adhere to physical activity and obtain the recommendations in the *Scientific Exercise Guidelines for Adults with Spinal Cord Injury*. Over an extended period of time physical activity participation becomes increasingly unstable within the adult SCI population (Sweet et al., 2012). van den Berg-Emons et al. (2008) findings indicate an upward trend of physical activity levels in adults with SCI increasing during inpatient rehabilitation, however, results revealed a decrease level of activity upon discharge from rehabilitation and continued to decline steadily during the first year after discharge from rehabilitation (van den Berg-Emons et al., 2008). At a one-year follow-up, the majority of adults with SCI who participated in the study did not engage in 30 minutes of daily physical activity, and the level of physical activity in those who did was distinctly lower than the general adult population (van den Berg-Emons et al., 2008).

Sweet et al. (2012) also examined physical activity participation trends within the SCI population, identifying four physical activity patterns over an 18-month period of time; inactive, increase, decrease, and stable activity. Categorization was generated based on the data yield indicating 22% of adults with SCI report no engagement in physical activity and 32% report engagement in some physical activity over 18 months. Interestingly, 32% of participants reported some engagement in physical activity at the start of the study, but then stop their physical activity participation after 18 months, whereas 14% of the adults with SCI report no engagement in physical activity at the start of the intervention, but some engagement at 18 months (Sweet et al., 2012). The evidence of this particular study illuminates the instability of physical activity

participation in the population. Only an approximate 44% of adults with SCI met Marcus et al. (2000) description of a successful maintainer, by increasing their physical activity from a completely sedentary behaviour, or demonstrating persistence in their physical activity participation, and continue to routinely engage in physical activity beyond a six-month period of time. Additionally, these findings provide support to previous evidence indicating that physical activity patterns remain inconsistent within the adult SCI population.

As a means to evaluate if community interventions or external support could aid adults with SCI physical activity participation, Arbour-Nicitopoulos et al. (2014) evaluated the effectiveness of physical activity programs via telephone counselling. This program was delivered to any adults with SCI interested in physical activity regardless of if they were active or inactive. Arbour-Nicitopoulos et al. (2014) reported that telephone communication with adults with SCI enrolled in a community-based physical activity program may have assisted participants' motivation to maintain their engagement in regular physical activity. Over a six-month period of time, nearly 50% of participants enrolled in the community physical activity program reported an increase in physical activity participation and some assistance towards increasing their motivation to remain physical active. The increase in physical activity participation among participants suggest that telephone counselling could be beneficial to help adults with SCI increase and maintain their physical activity (Arbour-Nicitopoulos et al., 2014).

Although there was a slight increase in motivation to maintain physical activity participation, the results were not statistically significant (Arbour-Nicitopoulos et al., 2014). Additionally, the study did not conduct a follow-up after the six-month period of time, thus unable to assess the long-term impact, or maintenance, of the service provided (Arbour-Nicitopoulos et al., 2014). Unfortunately, the absence of a long-term evaluation of outcomes, as



noted in Arbour-Nicitopoulos et al. (2014) study, is common as few studies have examined the long-term effects of participation in community based physical activity and mobility programs for the adult SCI population (Best et al., 2017). Best et al. (2017) suggest that there is an evidence gap in understanding the long-term outcomes of interventions and community initiatives in support of physical activity participation in the adult SCI population, as there is an absence of longitudinal evaluations of adherence to physical activity participation.

Bremer et al. (2021) study is of one of the few current studies that examined physical activity maintenance as a follow-up to a previous physical activity intervention to the adult SCI population. Specifically, they followed up with participants 12 to 18 months after completing one of two physical activity counselling interventions. The goal of the study was to understand if physical activity intervention can lead to sustained behaviour change and which aspects of the intervention promoted long-term physical activity participation and motivation (Bremer et al., 2021). Results originally showed the intervention group having greater physical activity participation than the control after the eight weeks (Chemtob et al., 2019). In this 12 to 18-month follow-up study, findings from Bremer et al. (2021) demonstrate that the intervention group maintained higher physical activity participation than the control group. Participants from the respective studies reported increased autonomous motivation, barrier self-efficacy, and competence towards physical activity, illustrating that providing guidance and support towards adults living with SCI initiation and engagement in physical activity can increase, and sustain, physical activity participation. Such findings demonstrate that physical activity maintenance can occur in the adult SCI population if proper physical activity guidance and tools are provided and utilized by a person living with SCI (Bremer et al., 2021).

Currently, research is limited in understanding how to best initiate and maintain physical activity participation in the adult SCI population over an extended period of time (Conner & Norman, 2017; Martin Ginis et al., 2016). To date, interventions within the current literature have remained focused on short term participation and associated outcomes (Best et al., 2017). Although evidence indicates that community-based physical activity programs are effective, the longevity of physical activity interventions and their effects toward physical activity maintenance have yet to be examined (Best et al., 2017).

Evidence concurs that there is a lack of maintenance to physical activity participation amongst the adult SCI population. To date, much of the research has focused on the experimental phase of physical activity interventions, and not towards long-term participation and maintenance of physical activity in the adult SCI population (Conner & Norman, 2017; Martin Ginis et al., 2016; Todd & Martin Ginis, 2019). Researchers and health care providers express that attention cannot solely be given to the 50% of the SCI population that are inactive. Efforts must also support those who are currently physically active so that they continue to maintain their physical activity level and participation (Conner & Norman, 2017; Todd & Martin Ginis, 2019). A greater understanding of the factors that facilitate adherence to physical activity participation among the adult SCI population is needed.

#### ***2.41 Facilitators for Physical Activity Maintenance***

As a means to provide additional understanding of the concept of maintenance, and examination of its current use in research, Kwasnicka et al. (2016) report five themes related to maintenance of a behaviour. First, a behaviour is more likely to be sustained if reinforcement is provided for immediate and affective outcomes rather than long-term, rational outcomes. Second, maintenance of a behaviour is stronger if a person can successfully monitor and regulate

the new behaviour. Third, a person whose psychological and physical resources are plentiful are more successful at maintaining a behaviour. Fourth, the behaviour has to be habitual, and the behaviour is supported by automatic responses to relevant cues. Lastly, a supportive environment and social support is present as people tend to maintain behaviour which is in line with relevant social change. Considering the themes listed, it is possible that the presence of some or all of these key components of maintenance could contribute to a person motivation and behaviours associated with maintaining their physical activity participation. There is evidence outlining facilitators of adopting and maintaining physical activity participation that align with these themes, primarily in the general adult population.

Motivational constructs are suggested to be facilitators for individuals in maintaining their behaviours, as motives enable gratification that reinforces the behaviour rather than the individual solely evaluating their experience of change (Kwasnicka et al., 2016). Within non-SCI populations, Amireault et al. (2012) identified in their systematic review that self-efficacy and intentions were higher among the general adult population who maintain their physical activity participation in comparison to those who experienced relapse. Further, individuals' who had high positive outcome expectancy for engagement in physical activity sustained their participation if it was coupled with high satisfaction for physical activity engagement. Maintainers who experienced positive outcome expectancy held more positive attitudes, and perceived more positive and less negative consequences towards physical activity, in comparison to those who relapse (Amireault et al., 2012). Intrinsic and extrinsic motivations also contributed to participants' physical activity engagement, including the importance of having a variety in choice of exercise, among physical activity maintainers post-cardiac rehabilitation (Sweet et al., 2019). Physical benefits received from on-going physical activity participation, such as improvement or

preservation of muscular fitness, and preventing physical decline, also had strong, positive influence in adults' behaviour beliefs toward physical activity maintenance (Huffman & Amireault, 2021). Additional positive outlooks towards continued engagement in physical activity are reported to stem from additional, external support.

The cardiac rehabilitation population express that receiving social support from several different parties such as family, peers, and rehabilitation or health care professional support current and previous research in their positive association with exercise maintenance (Sweet et al., 2019). Huffman and Amireault (2021) identify that immediate emotional benefits and instrumental support (e.g., knowledgeable trainers, having someone to go exercise) is more relevant to sustaining physical activity participation among the elderly population. Whereas emotional support (e.g., spouse or peers providing encouragement) is increasingly helpful for *reengagement* in physical activity after a setbacks or absence from engagement (Huffman & Amireault, 2021).

Also, when social influences such as opinions, emotional stress, and behaviours are shared or encouraged by others, there is an increase likelihood of an individual maintaining the behaviour (Kwasnicka et al., 2016). In order to maintain a new behaviour, however, a sense of relatedness must be developed. By creating this sense of relatedness, behaviour change is promoted and an increase sense of control is gained by the individuals allowing for behaviour maintenance to continue even when the social support is not present (Kwasnicka et al., 2016). Through social change and relatedness, new behaviours can become routinely embedded into an individual's everyday life (Kwasnicka et al., 2016). Evidence suggest that acquiring self-regulatory skills, in addition to social support, can aid in physical activity maintenance.

Current evidence within the general adult physical activity maintenance population supports that increased engagement or use of self-regulatory skills are strongly associated with behaviour maintenance (Amireault et al., 2012). The development of such skills requires time and continued engagement in the selected health behaviour (Marcus et al., 2000). Engagement in an activity over an extended period (i.e., engagement in the behaviour for longer than six months) aids in a person's confidence and ease in participating in the activity (Amireault et al., 2012; Marcus et al., 2000). Moreover, engagement in previous physical activity, either structured interventions or unstructured participation, has been reported to aid in the development of continued physical activity engagement, allowing for a more favorable transition to physical activity maintenance (Amireault et al., 2012).

Also, within the cardiac rehabilitation population particular behaviours such as habits, action planning, and self-monitoring have been reported to aid in facilitating exercise maintenance (Sweet et al., 2019). The reported outcomes and motives experienced by physical activity maintainers, in conjunction with the regulatory skills developed, provides further support in understanding the behaviours that facilitate physical activity maintenance (Amireault et al., 2012; Conner & Norman, 2017). Although there is an understanding as to what contributes to the general adult population engagement in physical activity maintenance, does the same understanding of population specific facilitators and motives apply for the adult SCI population?

#### ***2.42 Physical Activity Maintenance among the Spinal Cord Injury Population***

Literature pertaining to physical activity maintenance among the adult SCI population is limited. The available literature suggests that certain behaviours and environmental conditions can lead to on-going participation in physical activity by adults with SCI. Kerstin et al. (2006) identified some conditions, or motivational factors, that lead to physical activity participation for

adults with SCI, including personal enjoyment, fitness, competition, social interaction, and maintaining positive physical and mental health. Moreover, rehabilitation specialists support such statements, emphasizing that physical activity engagement that can allow an individual to feel physical and mental health benefits of an active lifestyle, in addition to being fun and enjoyable, contributes to the motivation to sustain physical activity participation (van den Akker et al., 2019).

Relying on the physical activity adoption literature in SCI, research hints that the desire to engaging in physical activity stems from positive attitudes, engaging in preferred means of activity, improving one's self-efficacy, having autonomous motivation, and social support (Blauwet, 2019; Rocchi et al., 2017). Equitable participation, a sense of belonging, opportunities for independence, in addition to having a combination of high self-efficacy and low motivation barriers, has reported to lead to greater physical activity participation amongst individuals with physical disabilities and SCI (Blauwet, 2019; Kerstin et al., 2006; Rocchi et al., 2017). For wheelchair users specifically, balance in daily life, and the balance between physical activity and periods of rest, is an important facilitator for sustained physical activity participation (van den Akker et al., 2019).

Moreover, social support is connected to increased life satisfaction, subjective well-being, and quality of life among adults with SCI (Muller et al., 2012; Sweet et al., 2016). A supportive person who encourages or provides assistants to a person living with an SCI is an important aid in overcoming barriers (Kerstin et al., 2006). Peer support specifically has been shown to have an impactful role in helping adults with SCI adjust to life after injury, and enhancing participation, coping strategies, and greater life satisfaction in meaningful aspects of their lives after injury (Muller et al., 2012; Sweet et al., 2016). Individuals with SCI who have

more social support, reciprocal relationships, and peer support are more likely to be interested in and engage in physical activity (Kerstin et al., 2006; Muller et al., 2012). The opportunity for individuals with SCI to view other people with disabilities engage in physical activity provides a realization of the possibility that they too can be physical active (Kerstin et al., 2006). The role modeling of positive, healthy behaviours and identifying good examples set by others living with SCI strengthens an individual living with SCI self-efficacy and self-confidence among individuals with SCI. The presence of role models and social support from other fosters confidence and encouraging attitudes for adults with SCI towards participating in physical activity and recognizing that it is possible to live a healthy, fulfilled life (Kerstin et al., 2006). The positive attribution peers and support from others have towards adults with SCI, particularly towards physical activity and healthy living, is highly encouraging, however, it remains unclear if social support contributes to physical activity maintenance among adults with SCI.

Although several facilitators have been reported to have strong associations with maintaining physical activity participation, the long-term application of maintenance behaviours from rehabilitation can be more difficult to carry-out (Sweet et al., 2019). The acquisition of intentions and skills associated with adopting maintenance behaviours can occur during rehabilitation. However, transitioning from having motivation to the utilization of acquired skills of engaging in a behaviour change can be difficult if an individual's intentions to change their behaviour, or tailoring of physical activity interventions are not present (Martin Ginis et al., 2013; Sweet et al., 2019). Movement from a motivational phase of engaging in physical activity to a stage of choosing to maintain physical activity participation requires personalization of physical activity and reinforce self-regulation to aid the in the transition and maintenance of the behaviour change (Martin Ginis et al., 2013). Exercise and health care professionals voice that

the particular regulatory skills facilitate exercise maintenance (Sweet et al., 2019). Similar findings have been addressed in SCI population, as consistently high levels of planning are considered vital to sustain physical activity participation, including on-going acts of self-regulation and self-monitoring when engaging in the behaviour (Martin Ginis et al., 2013). Exercise professionals in a cardiac rehabilitation setting expressed that transitioning from rehabilitation to daily life should include conducting further follow-up assessments and collaborating between health and exercise professionals to allow for long-term impact on patients' exercise levels (Sweet et al., 2019).

It has been identified that the adult SCI population are inactive and experience increase frequency of relapse to physical activity participation (Martin Ginis et al., 2018; Rocchi et al., 2017). It is uncertain, however, as to what specific conditions allow for physical activity maintenance among adults with SCI, as little information about physical activity adherence has been identified within the SCI literature (Kerstin et al., 2006; Todd & Martin Ginis, 2019). In comparison to the general adult population, there is less of an understanding as to why adults with SCI continue to engage in physical activity and what specific condition(s), if any, allow for physical activity maintenance in the SCI population. Less is known if the motivational variables, regulatory skills, and, most importantly, the long-term engagement in an activity identified in the general physical activity maintenance population occur and promote physical activity maintenance in the adult SCI population (Gaspar et al., 2019). A greater understanding of the how and why of maintenance to physical activity participation is required within the adult SCI population (Best et al., 2017).



**Chapter 3: Manuscript**

**Exploring Physical Activity Maintenance Among Adults with Spinal Cord Injury**

Tayah M. Liska, Haley Flaro, Mathieu Stever, & Shane N. Sweet

### **Introduction**

A spinal cord injury (SCI) is defined as damage to the spinal cord resulting in complete or incomplete sensory, motor, and autonomic dysfunction to affected nerves within the body. The damage to the spinal cord, resulting in a SCI, can be caused by a traumatic or non-traumatic event (Singh et al., 2014). A SCI leads to lifestyle changes including the use of a mobility aid such as a walker, crutches, or wheelchair and changes to personal care routines. Individuals with SCI may also face accessibility barriers within the physical environment, impeding individuals with SCI with the ability to engage within their community (Best et al., 2017; Mascarinas & Blauwet, 2018; Sweet et al., 2012; Todd & Martin Ginis, 2019). One of several daily living activities that has been shown to decline when a person is diagnosed with a SCI is engagement in physical activity, defined as any bodily movement produced by the skeletal muscles that increases energy expenditure and heart rate (Caspersen et al., 1985). Considering the broad definition of physical activity, the operational definition of physical activity in the context of this study will be synonymous with leisure-time physical activity (LTPA). Leisure-time physical activity is a subset of physical activity, defined as physical activity that an individual chooses to do during their free time (Marin Ginis et al., 2010).

Adults with SCI report significant decrease in their physical activity participation, and greater physically deconditioned, than the general population, including other physically disability populations (Martin Ginis et al., 2018; Rocchi et al., 2017). The decrease or cessation of daily physical activity amongst adults with SCI often occurs at the time of diagnosis and rehabilitation (Best et al., 2017; Sweet et al., 2012; van den Berg-Emons et al., 2008). Evidence indicates that upon discharge from rehabilitation, and as age and years post injury begin to

increase, adults with SCI choosing to participate in physical activity decreases (Martin Ginis et al., 2010; Rocchi et al., 2017).

Factors that result in decreased participation to physical activity also include increased number of unique physical and psychosocial barriers resulting from an SCI (Kerstin et al., 2006; Martin Ginis et al., 2018; Todd & Martin Ginis, 2019). Physical barriers to physical activity include a lack of accessible transportation, inadequate accessibility in facilities, commuting long-distances to accessible facilities, as well as poor outdoor climate and environmental terrain (Blauwet, 2019; Kerstin et al., 2006). Psychosocially, decrease of self-efficacy or motivation, decreased enjoyment or beliefs towards physical activity, unsafe neighborhoods, and insufficient support from others have been reported as barriers to physical activity engagement (Kerstin et al., 2006). Additional barriers to physical activity include lack of suitable, or adaptive, physical activity programming and settings (i.e., fitness centers) within the community (Bonnell et al., 2021). The compounding effects of the physical, psychosocial, and environmental barriers contributing to low physical activity rates are concerning in the SCI population given the increase occurrences of chronic diseases and decrease reports of personal well-being (Blauwet, 2019; Noonan et al., 2014).

Evidence-based physical activity guidelines have been established to assist researchers and health care professionals in prescribing, evaluating, and promoting physical activity within the SCI population. *Scientific Exercise Guidelines for Adults with Spinal Cord Injury* recommend that, for fitness benefits, adults with SCI engage in a minimum of 20 minutes of moderate to vigorous cardiovascular exercises twice a week, in addition to three set of strength-training exercises for each functional major muscle group three times a week (Martin Ginis et al., 2018). Additionally, for cardio-metabolic health specifically, the *Scientific Exercise Guidelines*

*for Adults with Spinal Cord Injury* recommend individuals engage in 30 minutes of moderate to vigorous aerobic exercises three times a week (Martin Ginis et al., 2018).

With the development of the *Scientific Exercise Guidelines for Adults with Spinal Cord Injury*, recent SCI and physical activity literature concur with previous evidence that adults with SCI are by-in-large inactive. Evidence indicates that approximately 50% of adults with SCI engage in zero minutes of physical activity, whereas approximately 12% of adults with SCI meet or exceed the recommendations within the fitness guidelines (Best et al., 2017; Martin Ginis et al., 2010; Rocchi et al., 2017; Sweet et al., 2012).

Adults with SCI who engage in regular physical activity experience improvements in their physical fitness including increases in cardiovascular endurance, muscle mass, and muscular strength (Blauwet, 2019; van der Scheer et al., 2017). Additionally, from an intrapersonal perspective, individuals with SCI report experiencing improvements in their physical and psychosocial well-being from continuous participation in physical activity (Carroll et al., 2014; Latimer et al., 2004; Tomasone et al., 2013). Individuals with SCI who have more social support, reciprocal relationships, and peer support are more likely to be interested in and engage in leisure activities (Muller et al., 2012). Equitable participation, a sense of belonging, opportunities for independence, autonomous motivation for engaging in physical activity, in addition to having a combination of high self-efficacy and low motivation barriers, has reported to lead to greater physical activity participation amongst individuals with physical disabilities and SCI (Blauwet, 2019; Kerstin et al., 2006; Rocchi et al., 2017).

Despite the literature stating the benefit of physical activity programming for on-going participation and adherence to physical activity, the longevity of such positive strategies and community-based programming initiatives has yet to be examined (Best et al., 2017). To date,

much research has focused initiation and short-term outcomes of adults with SCI to engage in physical activity, and not towards the behaviours and actions associated with the maintenance of physical activity participation (Conner & Norman, 2017). Literature pertaining to physical activity maintenance among the adult SCI population is limited. Kerstin et al. (2006) identified some conditions, or motivational factors, that lead to physical activity participation for adults with SCI, including personal enjoyment, fitness, competition, social interaction, and maintaining positive physical and mental health. Rehabilitation specialists support such statements, emphasizing that physical activity engagement that can allow an individual to feel physical and mental health benefits of an active lifestyle, in addition to being fun and enjoyable, contributes to the motivation to sustain physical activity participation (van den Akker et al., 2019). However, the long-term application of maintenance behaviours from rehabilitation can be more difficult to carry-out (Sweet et al., 2019). Transitioning from having motivation to the utilization of acquired skills of engaging in a behaviour change can be difficult if an individual's intentions to change their behaviour, or physical activity interventions, are not present (Martin Ginis et al., 2013; Sweet et al., 2019). It is currently unclear what conditions are necessary to maintain an adopted health behaviour and prevent relapse (Amireault et al., 2012).

The adult SCI population is inactive, and experience increase frequency of relapse to physical activity participation (Martin Ginis et al., 2018; Rocchi et al., 2017). In comparison to the general adult population, there is less of an understanding as to why adults with SCI continue to engage in physical activity and what specific condition(s), if any, allow for physical activity maintenance in the SCI population. Less is known if the motivational variables, regulatory skills, and, most importantly, the long-term engagement in an activity identified in the general physical activity maintenance population occur and promote physical activity maintenance in the adult

SCI population (Gaspar et al., 2019). To date, much of the research has focused on the experimental phase of physical activity interventions, and not towards maintenance of physical activity in the adult SCI population (Conner & Norman, 2017; Martin Ginis et al., 2016; Todd & Martin Ginis, 2019). Researchers and health care providers express that attention cannot solely be given to the 50% of the SCI population that are inactive. Efforts must also support those who are currently physically active so that they continue to maintain their physical activity (Conner & Norman, 2017; Todd & Martin Ginis, 2019).

Considering an absence of information regarding maintenance to physical activity among adults with SCI, the examination of physical activity maintenance in the adult SCI population should be further explored. Therefore, the purpose of the research project was to gain further understanding of adults with SCI who maintain physical activity participation. The research question of this study is *how* and *why* do adults with SCI maintain their participation to physical activity?

## **Methods**

### **Integrative Knowledge Translation**

Meaningful engagement between researchers and community organization and users in conducting and disseminating research findings that are most applicable and useful in research partnership (Gainforth et al., 2021). Integrated Knowledge Translation is important and unique approach to research translation because it aims to ensure that empirical research is translated into practice by engaging research users as partners throughout the entire research process (Gainforth et al., 2021). Integrated Knowledge Translation aligns with disability communities with an effort to enhance users' empowerment and engage in real-world problem solving to improve the relevance and outcomes from research endeavors (Gainforth et al., 2021).

From the onset of the design of this study, the engagement of a community partner was recognized as being valuable in understanding the community need in further insight on physical activity maintenance among the adult SCI population. In conversations with Ability New Brunswick and Para New Brunswick Sport and Recreation, the organizations expressed interest in gaining a greater understanding of physical activity among their SCI members. Ability New Brunswick is a provincial organization that provides services and a variety of community supports to individuals living with SCI or other physical disabilities. Para New Brunswick Sport and Recreation is a partner of Ability New Brunswick, leading the specific service of coordination and physical activity programming to support community members living with physical disabilities engagement in parasport or adaptive leisure physical activities.

Using an Integrated Knowledge Translation approach, we had on-going, meaningful conversation with Ability New Brunswick about their interest, perspective, knowledge, and contributions in assisting with this research study. These conversations allowed for a deeper understanding about how the study could provide value to the organizations to enhance physical activity promotion and participation among their community. After Ability New Brunswick expressed interest in understanding more about physical activity maintenance in SCI, we focused our conversations to ensure the research question addressed their needs, and that the research approaches and methods were feasible. A representative from Ability New Brunswick also engaged in pilot interviews to provide feedback on the interview guide and interview style of the primary researcher. Once both community partners and researchers were comfortable with the research program, recruitment and data collection began. Ability New Brunswick and Para New Brunswick Sport and Recreation assisted with recruitment and provided feedback on the preliminary analyses. We will be working with our partners in how to best disseminate this

knowledge to their service members.

### **Design**

A qualitative method was selected for this study. Qualitative research is a form of social inquiry centered on understanding and interpreting the ways people make sense of their experiences to create a stronger understanding of the questions and topics (Smith & Sparkes, 2016; Sparkes & Smith, 2014). Thus, qualitative research uncovers the significance of a phenomenon from the viewpoints and actions from a person's, or peoples', lived experiences in relation to the time, place, and position in which they are situated (Sparkes & Smith, 2014).

A multiple case study was selected as the primary methodology for this qualitative study. Yin (2018) reports that as a research question increasingly seeks to explain some contemporary circumstance of *how* and *why* of a social phenomenon, the use of case study research will become increasingly relevant. A case study design focuses on a single phenomenon within its real-life context, allowing for an in-depth exploration from multiple perspectives, revealing the complexity and uniqueness of a particular project, policy, or system (Smith & Sparkes, 2016; Yin, 1999). A multiple-case study design is appropriate when the same phenomenon is thought to occur in a variety of situations and individual circumstances and provide opportunity for the comparison between knowledge, perspectives, and phenomena with regards to the research question (Yin, 1981; Yin, 2012). For this research project, the use of a multiple-case study approach provided a meaningful way to answer "how" and "why" adults with SCI maintain their physical activity participation.

### **Paradigmatic Approach**

This multiple-case study was grounded in a constructivist paradigm, adopting a relativist ontology and subjective epistemology, recognizing that those who participate with the research



inquiry can contribute vast and valuable information that is unbeknownst to the researcher (Guba & Lincoln, 1994; Sparkes & Smith, 2014). Findings from the on-going interactions between the researcher and the participants aimed to understand the individual perspectives and unique mental constructs that each participant has to offer to collectively address the research question (Goertz & Mahoney, 2012; Guba & Lincoln, 1994). Through the investigation of the study, insights were gained from the participants about how and why they maintain their physical activity participation while living with a SCI. Alongside this ontological framework, the epistemology of the research is positioned as subjective, as the researcher holds the belief that their interactions with participants are highly valued in driving the research outcomes (Guba & Lincoln, 1994). Within a subjective epistemology, the researcher and the participant are linked through their interactions. The research findings are co-created and constructed through these interactions (Guba & Lincoln, 1994). Receiving and interpreting in-depth knowledge from adults with SCI as to why and how they have remained committed to maintaining their physical activity participation was quintessential to this study. In light of this paradigm, a multiple case study design was chosen because it allows for a hermeneutical understanding and dialectical exchange to occur amongst the researcher and participants about their experience of physical activity maintenance. It also enables a greater interpretation and understanding of the multifaceted, constructed realities, and experiences held by participants (Sparkes & Smith, 2014).

### ***Researcher's Positionality***

With consideration given to the paradigmatic approach of the research project, consideration of my own experiences and influences should be provided to give further understand the selection of paradigm and my positionality towards the study. Prior to attending

McGill University, as an undergraduate student, I was involved in service learning projects with community partners that has helped establish adaptive physical activity programs within the community for children with disabilities. Community engagement included using new assistive devices as a means for creating inclusive ways for the students to be physically active and teaching adaptive swimming lessons to elementary students with disabilities.

Regardless of my past experiences of working alongside individuals with disabilities or own knowledge of physical activity, I do not live with an SCI and cannot completely understand the reality and unique perspectives of a person living with SCI. I recognize that adults living with SCI who engaging in routine physical activity have knowledge and a perception that could not be hypothesized or measured by a person who does not live with an SCI, such as myself. With recognition of my positionality, and the selection of a qualitative method for this study, the findings from this study provided information, and opportunity to learn, directly from someone who engages in physical activity while living with SCI.

### **Multiple-Case Study Design**

Yin (2018) reports that as a research question increasingly seeks to explain some contemporary circumstance of *how* and *why* of a social phenomenon, the use of case study research will become increasingly relevant. Multiple-case study methodology provides additional options for the comparison between knowledge, perspectives, and phenomena with regard to the research question (Yin, 2012). Each case involved in a multiple-case study aims to examine individual components within a case to determine a complementary facet of the larger research question (Yin, 2012). Contributing to the components within each case, the use of boundaries, proposition, and rivals within each case allows the researchers to focus on relevant evidence, and reject certain arguments and information (Yin, 2018).

***Bounding the Case***

A case is “bounded” by the specific selection of the time, place, and entity of the phenomenon (Sparkes & Smith, 2014). The boundedness of the case removes unwanted, excess features that may surround the particular knowledge or experience of the participant within the inquiry (Sparkes & Smith, 2014). In this study, the cases were bounded by adults with SCI who continue to engage in their preferred means of physical activity for one or more years after the completion of rehabilitation for their SCI diagnosis (van den Berg-Emons et al., 2008). Each case will also focus on adults with SCI who use a manual wheelchair to limit the heterogeneity of mobility in SCI.

***Rivals***

Yin (2018) supports the integration of rival positions into all case study research. Rival explanations include possible implications of other available data or theories that may challenge the case-study results. Consideration of plausible rival explanations strengthens case quality. As the more rivals that are addressed and then rejected, the stronger the case findings (Yin, 2018). For this study, existing literature was used as rivals. Findings of the cross-case analysis were compared to existing statements of how and why individuals within the general population engage in physical activity maintenance, as well as topics of physical activity maintenance in physical disability and physical activity literatures.

***Participants***

Yin (2018) suggests that the number of cases selected for a multiple case study should remain small to allow for an in depth understanding of the individual phenomena within each case, in addition to the feasibility of literal replication of the methods within each case. Also, in conversation with our community partner Ability New Brunswick, they agreed that a small

sample would be feasible for participant recruitment. As a result, we agreed that a total of four cases would be feasible for the organization, which aligned with the recommendations of a small sample size for multiple case studies.

A purposeful sampling technique was used to recruit adults (18 years or older) with SCI who speak English, who use a manual wheelchair, and report meeting or exceeding the recommendations of the *Exercise Guidelines for Adults with Spinal Cord Injury* for one or more years since completion of rehabilitation. Participants with SCI were also to identify someone who facilitates their physical activity participation (i.e., family member, teammate, coach, friend) to participate in the study. Upon receiving McGill Research Ethics Board approval (See Appendix A), Ability New Brunswick contacted members listed within their central database who were eligible for the study. From this list, members were contacted to be informed of the study and asked if they consented that Ability New Brunswick and Para New Brunswick Sport and Recreation shared their name and email address to T.L., the primary researcher.

### ***Procedure***

When a member expressed interest in participating in the study, they were screened by T.L. to determine if they met the physical activity requirements outlined in the *Exercise Guidelines for Adults with Spinal Cord Injury*. The physical activity screening questions was adapted from the Leisure Time Physical Activity Questionnaire for People with Spinal Cord Injury (Martin Ginis et al., 2012b). Screening questions address the weekly frequency, time, and type of physical activity potential participants engage in, in addition to reporting how long, (i.e., months or years), they have been engaging in physical activity (see Appendix B). Also, potential participants had to be able to identify a person in their life who facilitates their physical activity. If the member identified meeting the outlined criteria, they were invited to provide informed

consent to participate (see Appendix C). After providing informed consent, the first interview was scheduled, and participants were asked to contact a facilitator to obtain permission that T.L. could contact them and invited them to provide informed consent to participate (see Appendix D). After the first interview, the adults with SCI took photographs of their environment and completed physical activity diaries, which they submitted to T.L. prior to the second interview. As an accommodation for the COVID-19 pandemic and completing data collection remotely, participants were asked to provide physical activity diaries and photographs as an alternative to observations. Also prior to the second interview, T.L. scheduled and completed one interview with the physical activity facilitator. All interview we conducted over Microsoft Teams. Interview recordings were saved to a password secure hard drive. To ensure confidentiality, all participants (adults with SCI and their physical activity facilitators) were assigned pseudonyms to label the data. T.L. journaled throughout the data collection and transcription phases (See Appendix E for a visual sequence with description of the procedure listed above).

## **Data Sources**

### ***Multiple Semi-Structured Interviews***

Three one-on-one semi-structured interviews were conducted in this study. Each interview consists of its own interview guide with potential probing interjections to meet the overarching objective of the research and to maximize the participant's response (Smith & Sparkes, 2016; Sparkes & Smith, 2014). The first interview occurred with the adult with SCI to understand their personal background (e.g., their SCI, occupation) and physical activity history, including an initial conversation about the factors helping them maintain their physical activity (see Appendix F). The second interview occurred with the person whom the participant identified as someone important who facilitates, or supports, their physical activity (see

Appendix G). The interview with the facilitator served as an additional data source to gain additional depth and breadth in understanding the facilitators' role in promoting or supporting physical activity maintenance of the participant. After the first two interviews were completed, the conversations were analyzed to highlight key points within the responses that should be emphasized or elaborated in the third interview. Also, the third interview took place after the journal notes and photographs were provided by the adult with SCI (see sub-headings below) to allow a discussion about interactions or encounters documented. The third interview was a follow-up discussion with the adult with SCI to obtain detailed descriptions and experiences on the participants' reasons, efforts, and strategies used to maintain physical activity participation (see Appendix H).

### ***Photographs***

Visual methods, such as photographs, offer a different way of knowing the world, beyond the knowledge conveyed or constructed through written and spoken words alone. Visual methods serve as a unique form of data that allow for more vivid understanding of complex layers of meaning of participants' knowledge and realities (Sparkes & Smith, 2014). Participant-centered photographs allow the participants to document the photographs of their choosing to form the basis of conversation in a follow-up interview, increasing participation and involvement in the research process (Sparkes & Smith, 2014). For this study, the adults with SCI were asked to provide photographs of their physical activity spaces (i.e., gymnasiums, fitness centers, trails) and themselves (if a solo activity) or others (teammates) engaging in their preferred means of physical activity. The use of the photographs was to visually contextualize not only the physical environment where participants engage in their preferred means of physical activity, but also how participants continue to engage in physical activity.

### ***Physical Activity Diaries***

Diary methods allow for researchers to capture “life as it is lived”. Rather than participants recounting life events or feeling, diaries allow the participant to record the events and feelings as it occurs, or closer to the time of occurrence (Barlette & Milligan, 2021). Participant’s engagement in recording their experience as they occur can reduce recall bias and allow for data collection over an extended period of time (Barlette & Milligan, 2021). The adults with SCI were to provide journal notes of their on-going physical activity engagement over the course of the study. The use of a reflective journal by the participants was to capture participant’s thoughts, feelings, and perceptions of their physical activity maintenance. Considering the insight that could be relayed by the adult with an SCI from their perceptions of their physical activity engagement, reflective journaling provided an external perspective as to why they continue to engage in physical activity.

### ***Journaling***

With consideration for a reflexive process, and an additional source of data, T.L. journaled feelings, insights, and points for further inquiry, either with the participants or the literature throughout the entirety of the study. Journaling took place prior and after the completion of each interview, in addition to when the interviews were transcribed verbatim. Also, personal notations about the interviewer’s experience during the interview and perception of the participant’s response (both verbal and non-verbal cues) and emerging ideas from the interview, were documented in the journal notes. The journal notes were used to elaborate and synthesize the collective themes and concepts expressed by the participants.

## **Data Analysis**

While five specific analytic techniques are outlined by Yin (2018) for effective, high-quality case studies, the fifth technique, cross-case synthesis, or cross-case analysis, applies to the analysis of multiple-case studies and was pertinent for this study. Therefore, a cross-case analysis was selected as the method of data analysis for this study.

### ***Cross-Case Analysis***

In a cross-case analysis, the researcher compares and contrasts the results of each case to one another to generate understanding and explanation of the overall outcomes of the study (Yin, 2018). The desire of a cross-case synthesis is taking a “case-based” approach with the objective of understanding the meaning of the information within an entire individual case, and then compare the information to any within-case patterns across the entire collection of cases within the study (Yin, 2018). The initial within-case analysis often involves analysing the “hows” and “whys” of the data collected for each individual case (Yin, 2018). After doing so, the analysis proceeds to examine if there is a replicative relationship across the case study to decipher and discuss the differences contained in each individual case in the multiple-case study (Yin, 2018).

First, analysis of the individual cases took place. The data sources within each case were inductively coded to generate themes and highlight significant findings pertaining to the case. In doing so, the primary author adopted Braun et al.’s (2016) steps for thematic analysis for coding and analyzing the qualitative data: (1) familiarizing and coding; (2) theme development and refinement; and (3) writing the analysis. By transcribing verbatim each interview, reviewing and re-reading the transcripts, physical activity diaries, and journal notes, as well as examining the photographs provided, T.L. became increasingly familiar with the data. After, the transcripts,



physical activity diaries, and photographs were inductively coded to conceptualize the meaning of the written and oral statements made and to visually interpret the photos. Statements that were identified as having important, or valuable, information pertaining the participant's physical activity maintenance were coded. Notations were made alongside these initial codes about the insight captured in, or nuance to, the highlighted data. The coded data were then extracted and organized into categories based on similarities in the context of the data to develop overarching themes. Finally, the developed themes and content within the themes were refined to synthesise and illuminate the significant insights and findings pertaining to the participant's physical activity maintenance.

For the cross-case analysis, the themes of each individual case were compared across cases to examine conceptual overlap between the identified theme and content. Similar themes in the individual cases were then grouped together and re-named (if required) to create cross-case analyses themes. Within the cross-case themes, the individuality of the cases remained the focus, as a cross-case theme included similar and/or diverging experiences of participants. The findings for each case and the cross-case analysis are written in the results section to follow.

### **Rigor and Validity**

An important aspect of qualitative research is to ensure that approaches to the methodology demonstrate rigor to ensure reliability within the research process (Sparkes & Smith, 2014). Burke (2016) outlines that there are external criteria for the evaluation of qualitative research including evaluating credibility (establishing whether the findings are trustworthy or accurate), dependability (sustainability of the data overtime and under different conditions), transferability (inferences that extend beyond a particular set of findings), and confirmability (illustration that the interpretations of the findings are clearly derived from the

data itself). To ensure strength in the rigor and validity of the research, the four components of the external evaluation criteria outlined by Burke (2016) were followed. This criteria was selected because the critical approach of the external criteria is comprehensive enough to assess all aspects of methodological rigor across all forms of qualitative inquiry (Burke, 2016).

For credibility, the methods of prolong engagement, persistent observation, and triangulation of the data were utilized by the primary researcher to ensure credibility of the data. Also, the consistency in the data sources utilized for data collection in each case ensured that the stated research process was well established and trackable, confirming the dependability of the data. Upon completion of data collection and the transfer of recorded interviews into verbatim transcriptions, Prof. Shane Sweet, executive director of Ability New Brunswick, and manager of Para New Brunswick Sport and Recreation were used as critical friends to review and analyse the data, as well as the position and interpretation of the research. The research journal kept by T.L., used to record personal thoughts and experiences throughout the inquiry, ensured that the primary researcher remained reflexive throughout the entire study. The critical friends and the research journal were used to identify or report on the influence of the investigator's own background, perceptions, and interest in the research process. These reflexive processes insured confirmability of the recording of the results and interpretations of the data by the primary researcher. The combination of evaluations ensured the upmost rigor of the data, allowing for rich and robust results, central to the research question, be contextualized. The results present information that allows inference, or transferability, beyond the finding presented in this study.

## **Results**

### **Overview**

Each of the four individual cases are presented with an overview of the participant with SCI, followed by the identified themes and subsequent sub-themes as to why the participant with SCI engaged in physical activity maintenance, and then how they maintain their physical activity. The cross-case analysis follows a similar sequence of the presentation of the results. First, the common themes and sub-themes as to why participants maintain their physical activity, followed by the common themes and sub-themes as to how participants maintain their physical activity.

### **Case 1: Scott**

Scott is a 44-year-old man, husband, and father. Scott was diagnosed with a T12, incomplete SCI resulting from a motor vehicle accident. He uses crutches and a manual wheelchair as mobility aids. After his SCI, Scott went back to school to study business and has worked over 20 years in the private sector. Scott described himself as someone who has always loved sports prior and after his injury, always participating in a variety of sports and activities. During rehabilitation, Scott did a combination of resistance and aerobic exercises for an hour a day. After discharge from rehabilitation, Scott played on a national parasport team, and continued to play at a local, recreational level. Currently, Scott engages aerobic and strength training daily, alternating between using fitness equipment at home and attending local gym. During the winter, Scott plays sledge hockey in a local recreational league and cross-country sit-skis routinely. During the spring and summer, Scott uses his outdoor hand cycle and enjoys leisure activities, such as camping, with his family. Scott identified his wife, Claire as his physical activity facilitator.

### *The Joy of Being Active*

During our conversations, Scott's enthusiastic expression, joyful demeanor, and repeated statements of his genuine love for physical activity made it evident that the joy of being active was the overarching reason for Scott's physical activity maintenance. When asking Scott why he maintains his physical activity, he often responds, "I guess it just like, I don't know, it's stuff I love to do and when I'm doing it, I really enjoy doing it". Scott expressed that his joy of moving and being active is part of him: "I don't know, I couldn't imagine stopping cold turkey and do nothing. I'd go mad, I'd go mad". His joy of being active represents the overarching theme of this case as it permeates into the other themes below.

Scott's elation towards sport and physical activity has been stimulated by his competitive spirit, making it a predominate reason as to *why* he maintains physical activity. He loves competing against others and himself, "I still enjoy competing that's my main thing. I enjoy competing against people. I enjoy competing against myself." Scott's competitive spirit fuels his desire to be a better athlete and become a stronger person.

**Better athlete.** Throughout his national parasport career, Scott pushed himself to be better, challenging himself to surpass his teammates in skill development drills at practices and in competitions. Watching his teammates excel within their sport motivated Scott to improve his own performance as an athlete, "...and motivating as well too because I wanted to get better". Wanting to enhance his performance, Scott would set goals for himself to focus on, enhancing his motivation to improve as an athlete; "I see the level [my teammates] are at and I have that competitiveness in me like 'I got to be better than them, I got to be faster than them, I got to be quicker', and I hit that goal". Scott's focus to be a better athlete has enabled him to remain physically active over so many years.

**Stronger person.** Claire emphasized Scott's competitive nature has fostered an innate drive. She described Scott as a person who consistently pushes himself to become physically stronger since his SCI, "...especially his injury, [it] doesn't stop him from whatever he wants to accomplish. If anything it drives him forward more just to prove that he can". Scott chooses to engage in activities that he enjoys and provides a sense of fulfillment; "I think that's part of it. I think he's just, like I said an innate drive to feel good and just live every day to the fullest" (Claire). Scott's desire to improve physically has increased his mobility, ease of wheelchair transfers, and independence: "Build your strength to make it easier to transfer to and from, and also I was gaining more strength back in my legs".

Scott described himself as not being one to dwell on his injury: "When I ended up in the wheelchair, I adapted so I could still do them [sports]". He applied this same mentality to physical activity in seeking opportunities to be physically active and prioritizing that activity. Such an approach opened doors for Scott supporting *how* he can remain physically active.

### ***Seeking Opportunity***

Scott was never deterred in pursuing activities because of his disability, "I never shied away. Once I had the opportunity, I jump on whatever opportunity came my way". For example, Scott wanted to play elite parasport. To achieve that goal, Scott was told he had to gain competitive parasport experience before trying out for the Canadian national team. Scott directly contacted division-1 parasport teams in the United States to see if he could have the opportunity to compete and train at a division-1 level. Recently, Scott sought the opportunity to being active at home because of the COVID-19 pandemic. He ordered new at-home exercise equipment and went cross-country skiing during lockdown; "...he was all of a sudden doing research online

trying to get gym equipment and so every time we've locked down we'd seem to acquire more gym equipment" (Claire).

### ***Prioritizing***

Remaining healthy, both physically and psychosocially, was repeated as a reason to why Scott maintains his physical activity; "I love, first of all, to remain healthy. I think it all starts with being healthy in order to do stuff". As an effort to remain healthy, Scott explained how he maintained his physical activity. He prioritizes his physical activity engagement by firmly scheduling physical activity into his daily and weekly schedule; "I'm always working it around to fit it in". To keep his joy of being active, and maintain his physical activity participation, Scott mentioned that he purposefully engaged in a variety of physical activity. This variety of physical activities provides him options for alternatives if weather, transportation, or other circumstances makes it difficult to engage in his originally planned activity.

### ***Physical Activity Educator***

Remaining physically active within the community has been a way for Scott to help and support others with disabilities: "I love helping people. So if I wasn't active in sport or the gym I don't know how I could help people". Scott also sees himself as someone who is knowledgeable in adapted physical activity and who can share his lessons learned: "...his YouTube channel with all the different things that he's promoting. Promoting active lifestyle and just practical teaching of how to do certain transfers or how can somebody [with SCI] exercise" (Claire). Being engaged within his community, Scott recognizes the accessibility difficulties and advocates for the physical activity needs of his community: "...let's work together, let try to find a solution to you know have better access, that type of thing".

**Case 2: Eric**

Eric is a 34-year-old man, a veteran of the Canadian Arm Forces, and a full-time university student. Eric was involved in a motor vehicle accident, causing a T6 complete SCI. Eric attended rehabilitation twice. During his first admission to rehabilitation Eric recalled that he spent much of his time contemplating his injury, and re-admitted himself to rehabilitation shortly after discharge, recognizing he still had much to learn about living with an SCI. After rehabilitation, Eric went back to work, proud that in less than a year of his injury he was able to resume aspects of daily life prior to his injury. Prior to his injury, Eric described himself as being a near daily runner, and would engage in outdoor seasonal activities such as swimming.

Eric has become increasingly engaged in various means of physical activity, including wheelchair basketball and hand cycling. It was during his second admission to rehabilitation that he was introduced to parasport, which helped change Eric's outlook towards his life circumstances and increase his physical activity post-injury. Eric currently engages in hand cycling and resistance training at home or the university's fitness center three to four days a week for 30 to 60 minutes each time. During the winter, Eric plays sledge hockey recreationally. Eric identified his hand cycling mentor, Jake as his physical activity facilitator.

***Persistence***

Eric accredits his persistence as to why he has remained physically active after his SCI. Eric expressed encountering difficulties and uncomfortable circumstances while living with an SCI. However, these uncomfortable circumstances fostered his persistence. Eric pushed himself though such moments of discomfort, growing outside his comfort-zone: "...most of your growth in life comes from getting outside of your boundaries and getting uncomfortable. So it's what I try to tell myself is get comfortable with being uncomfortable". In doing so, Eric is driven to

carry-on with his daily life and activities that provide personal enjoyment, including his physical activity participation. Eric related his inherent intrinsic motivation and prioritization of physical activity to his persistent nature, and why he has maintained his physical activity.

**Intrinsic motivation.** Eric intrinsic motivation supports why he maintains his physical activity. He emphasized that he needs to have the willingness to continue to engage in physical activity, “I think a lot of it is intrinsic. Like yeah, I think definitely some of it has to be intrinsic or you’d sleep in. You wouldn’t get up or [would] take the easy way out that day, [and] not go train”. Eric described having the motivation to push himself beyond boundaries he or other may have towards his physical capabilities and physical activity participation, “...anything worth doing is worth doing 110%. You want to try to push the boundaries I guess, or I do. That's my mind set”.

**A priority.** Eric listed two main reasons as to why he keeps his physical activity a priority. First, Eric prioritizes his health, and maintaining his physical activity supports his physical strength, and optimize his functionality, quality of life, and life span: “Yeah, yeah. For longevity, for my future, to maintain my physical standards so I can continue to go to work and perform every day...”. Second, Eric feels he needs to be accountable to his physical activity engagement for it to remain a priority and thus he ensures that he allots time to continue to be active. “Otherwise just being patient and planning the time [to be active], I mean that’s really the only way I found to overcome [barriers to physical activity]”. The time Eric dedicates, and desire he has, to remain active has supported his physical activity maintenance.

### ***Time Management***

After his injury, Eric realised more time is needed to engage in daily living tasks, thus the importance of time management. Eric spoke about how he plans much of daily schedule,



including his daily and weekly physical activity: “Yeah. Just trying to keep a daily schedule, schedule it into my day”. Time management has been a strong tool for how he remains active, ensuring that physically activity is planned among his other commitments: “Yeah, with the work-life balance it’s just trying to squeeze [physical activity] in the morning or the evenings when I can”.

**Remaining disciplined.** Eric accredits remaining disciplined towards his pre-determined physical activity helps him maintain physical activity: “That's all mental. Yeah, focus and discipline”. Eric spoke of remaining disciplined, determined to persevere, when challenges or uncomfortable circumstances arise, such as environmental (e.g., wheeling through snow drifts) or social (e.g., riding a snowmobile with friends) barriers associated with living with a SCI. He does not let these challenges prevent or halt his physical activity engagement, “It's the boundaries you set for yourself. It takes a lot longer and more, more thought, more effort, but it can be done”. Although daily routines and engaging in physical activity takes a little longer, Eric remains discipline by putting forth his best effort and following-through with commitments. Doing so supports his goals towards self-improvement and increased fitness, and insures he remains physically active.

### **Case 3: Patrick**

Patrick is a 33-year-old man who was diagnosed with a T-5, T-6 complete, and C-6 incomplete SCI from a motor vehicle accident. Patrick was initially diagnosed with a T-5, T-6 complete SCI, but a second assessment during rehabilitation revealed a C-6 incomplete SCI, changing Patrick’s diagnosis to quadriplegic. Patrick was very physically active prior to his injury, participating in a variety of sports, but predominantly rugby. Patrick was offered a

position as a middle school rugby coach prior to his injury, and coaching became a driving goal to complete his rehabilitation.

Patrick described his physical activity initially after his injury as movement required while working as a rugby coach and at a summer camp: “So I would do two months of coaching and then two months of camp. So it was just four months of physical activity”. Patrick currently plays wheelchair rugby and had a well-established routine of attending the gym three to four times a week with his roommate, long-time friend, and identified physical activity facilitator Alex. However, Patrick’s physical activity has been disrupted due to gym closures, and the cancellation of the wheelchair rugby season, in light of the COVID-19 pandemic.

### ***Pragmatic and Determined***

Patrick has a pragmatic outlook and is determined to maintain his physical activity. He has a “get on with it” attitude, explaining that he does not dwell about managing his SCI and physical activity engagement. When he plans to go to the gym, or has wheelchair rugby practice, he follows through with his commitments and is determined to continue to be active: “It definitely helped having the determination of ‘if I want to do what I want to do, I have to get this done by a certain time’”. If a conflict arises, then he finds an alternative time to be active. His pragmatic and determined approach help him maintain his physical activity, but so does his love for rugby and desire to lead a healthy lifestyle.

**Love for rugby.** A reoccurring reason as to why Patrick coached rugby and continues to play wheelchair rugby is because his love for the sport: “As far as the physical activity, with rugby, I’ve decided that I’m going to do it [play rugby], so I continue to do it and I enjoy the actual games and stuff”. His pragmatic approach is also evident in the quote because his involvement in rugby is also due to the commitment he made to his team. However, the added

enjoyment he receives from being with peers, having the opportunity to meet people from across the country contribute to why he continues to play wheelchair rugby.

**Health and longevity.** A reoccurring topic in our conversations is that Patrick engages in physical activity to support a healthy lifestyle, especially as he gets older. Patrick's on-going physical activity has been to prevent deterioration or occurrence of health complications, as well as a longevity: "I just want to have good health in ten years. I don't want to be bed ridden because my health is so bad". When Patrick experiences a decline in his fitness, or long pauses in his physical activity routine, he has found pragmatic solutions to continue to be active and maintain his health. For example, Patrick recalled: "Today I noticed that going up the ramp into my house makes me feel tired... I plan on going up and down the ramp a bunch each day to help with that". (Patrick's journal notes). The ways in which Patrick has maintained his physical activity has been driven by his desire to remain healthy and prevent health complications over the course of his lifetime.

### ***Interactions with Community***

Patrick agreed the support from wheelchair rugby and disability community has contributed to his physical activity maintenance. Patrick raised an interesting perspective that the inclusive environment of parasport promotes positive socialization among the disability community: "Being disabled...you're always the minority in the room and it's really weird to go to a [parasport] situation where you're now the majority in the room". Having an inclusive environment for the disability community positively encourages members to continue to return, contributing to members' physical activity maintenance.

***Routine***

In line with this pragmatic outlook, Patrick described himself as someone who was very routine orientated. Having established a familiar routine that included physical activity has been supportive of how Patrick maintains his physical activity. Patrick and Alex both spoke about how they had a well-organized routine, going to the gym on particular days and times, that appeared to have made physical activity a natural part of the day: “When I was consistently going to the gym for a couple months at a time, [and] if I missed a week, it felt weird not going, and I didn't like that”. Having a schedule and routine enabled Patrick’s physical activity maintenance.

***Resumption of Physical Activity***

During the COVID-19 pandemic, Patrick has unfortunately experienced a cessation in his physical activity participation. However, Patrick expressed that he does not see any concerns about resuming his physical activity routine once health restrictions lift: “I don't think getting back into stuff is going to be that hard”. Having a strong physical activity routine beforehand, his pragmatic outlook, and determination would support his confident response in being able to resume his physical activity.

**Case 4: Andrew**

Andrew is a 20-year-old man, and full-time university student. He has a C5-C6 incomplete SCI due to a snowboarding accident. During our conversations, Andrew emphasised that sport has always been a part of his life, before and after his injury. He participated in “every school sport imaginable”, including badminton, volleyball, basketball, and hockey. Andrew played on the provincial soccer team and competed in the Kayaking national championship, with the goal of qualifying for the Olympics in kayaking.

Being highly athletic prior to his injury, Andrew recalled an eagerness to be more active during his rehabilitation, asking for more time in the gym and for his physiotherapist to add more weight to the resistance machines. Andrew joined a provincial parasport team after being introduced to the sport in rehabilitation. Andrew trains with Team Canada's Next Generation Program for his parasport, while attending university. His current training schedule has been reduced because of COVID-19 protocols, but attends weekly parasport practices, and engages in vigorous cardiovascular and strength training with teammates once a week. Additionally, Andrew engages cardiovascular and strength training, independently, three times a week. Andrew identified his coach and teammate, Cameron as his physical activity facilitator.

### ***Athletic Identity***

Sports have always been a part of Andrew's life: "I can't lose it both for the fact that I wouldn't know what to do with myself and the fact that I would probably drive myself mad if I didn't have it [sports]". He could not see himself parting ways with sports, especially after his injury. He identifies strongly with an athletic role and that sport is part of how he defines himself, supporting an athletic identity. Andrew's affinity for sports has contributed significantly to his physical activity maintenance.

**Passion for sport.** Andrew spoke that his passion for sports has been a predominate reason for his physical activity maintenance. Andrew's desire to play sports have always been his reasons for returning to training, practices, and his physical activity maintenance: "I think the passion aspect would be stronger and would always draw me back". When introduced to parasport during rehabilitation he fell in love all over again, as parasport allowed for his devotion and passion for competitive sport to shine through: "I was aching for [sport] and so when had

that opportunity to get into a sports chair, it was just one step closer back to where I wanted to be [competing in sports]”.

During each conversation, Andrew spoke with great enthusiasm about the joy he receives from competition and sports. His dedication to a competitive training schedule, physically demanding practices, and balancing his university courses with training is not seen as exhaustive. Rather, Andrew always remains eager and excited to participate in sport. Andrew’s long-time love for sport has enabled him to remain physically active.

**Gratification from sport.** Andrew describes obtaining many positive experiences from sport. He enjoys the team environment as sports provides a common ground for interacting with others and an opportunity to learn from peers, as mentioned by Cameron: “...he’s really open to learning from what I have to say and what other have to say”. Andrew also described playing sports in a high performance atmosphere as stimulating, fostering drive to push himself further: “I enjoy when we are training, to have an opportunity to push myself. It’s an opportunity, to be, yeah, goal orientated”. Andrew emphasized the gratification he receives serves as a physical and psychosocial outlet: “I’m definitely happier when I have the opportunity to do sports every once in a while”. Having sports as an outlet helps Andrew become focus towards other tasks, such as school work.

### ***A Committed and Ambitious Athlete***

Andrew’s competitive attitudes and commitment to parasport has contributed to explain how he remains active. He has a clear vision of a successful athlete and how to become a national parasport athlete. Having such a vision creates firm goals to better himself and support his desire to compete in sport: “There’s a vision that’s probably a part of [improving]. Probably a mix of specific, you know, goals and vision of where I want to be and improve...”. Andrew’s

competitive ambitions within parasport have contributed to him fully applying himself in training. Andrew commits to attend all practices and training sessions to continuously apply himself in effort to learn and be better as an athlete, as voiced by his coach, Cameron: “There definitely needs to be a drive there to commit that much, as much time that Andrew is to a single sport. It points to the passion and drive Andrew has to compete and be better”.

### ***Pursuing Excellence***

Andrew’s competitive drive, ambitions, and passion for sport have been key components towards his dedication to compete in parasport and pursuit for excellence as an athlete: “I aspire to dedicate a lot of time to get to the highest level of the sport I'm competing in. I have a drive to get there”. Andrew’s drive to improve and excel in sport is evident in his constant attendance at parasport practice and conditioning sessions, remaining focused and engaged during training, seeking feedback from his coach, and striving to meet or surpass the goals he sets for himself. Andrew’s pursuit for excellence as an athlete is an underlying reason for continuing apply the strong athletics skills and knowledge acquired of as he strives to improve as an athlete

“But definitely there's an added level when you are specifically looking to improve...you give yourself a little bit more drive to be able to implement that because you actually are interested in what's going on and want to, to improve yourself...”

### **Cross-Case Analysis**

#### ***Connecting Physical Activity to Improved SCI Function and Health***

All participants stressed the importance of physical activity participation for their daily functioning with an SCI and health. Participants linked the positive impact physical activity on facilitating transfers from their wheelchair, maintaining shoulder health for mobility, and minimizing occurrence for co-morbidities.

**Transfers.** “I wanted to move from my wheelchair to anywhere I had to transfer. You know, just common sense. Build your strength to make it easier to transfer to and from...” (Scott). Increasing and maintaining shoulder health and arm strength through physical activity participation to facilitate transfers was emphasized by participants. Physical activity helped reduce the likelihood of missed transfers and shoulder injury and decreased stress on their shoulder joints. Continued participation in physical activity also helped with weight management. They expressed that lower weight makes their daily transfers easier. The strong connection between physical activity and ease of transfers is therefore an important reason as to why the participants maintained their physical activity.

**Mobility.** Similar to transfers, participants spoke of maintaining their engagement in physical activity to maintain their strength to support their wheelchair mobility. Participants spoke of how maintaining their strength and weight management allowed for increased functionality and mobility. “By maintaining a weekly regiment of two to three days in the gym, that gives me a big edge over my upper body strength to be able to do things like [transfers and wheeling] ...” (Eric). The positive differences in mobility experienced by participants from engaging in physical activity has been a strong contributor as to why participants have maintained their physical activity participation.

**Preventing co-morbidities.** Participants acknowledged the increased likelihood of health complications and comorbidities associated with SCI. Participants spoke openly about their previous or current health complication including hip and joint pain, heart complications, and poor circulation. Participants recognized that physical activity was a behaviour within their control that can mitigate the occurrence of comorbidities and increase the longevity of their lives. “I just want to have, you know, good health in ten years. I don't want to be bed ridden because



my health is so bad” (Patrick), and: “Yeah, it's long term, and longevity, and suitability” (Eric). The positive outcomes towards their health, has been encouraging and validating for their continued engagement in physical activity.

### ***Planning Physical Activity***

All participants spoke about how they plan their physical activity either as making a schedule, following pre-planned parasport schedules, or establishing a personal routine. In addition to planning their physical activity, participants talked about ways they adapt their plans when needed. Eric and Patrick spoke about being malleable with their schedules allowed them to make changes in their day, including modifying their plan to do gentle movement at home or to wheel up and down an outdoor ramp. For, Scott, having a variety of types of physical activity allowed for greater options while planning to be active, whereas Andrew prefers a pre-determined scheduled from parasport practices. Regardless of how planning physical activity was executed by participants, all demonstrated the use and benefit of having a plan associated with their physical activity participation to support their on-going participation.

### ***Peer Support***

Participants enthusiastically spoke about the role of peers in supporting their physical activity engagement and navigating daily life with an SCI. The peer interactions while engaging in physical activity allowed them to learn and reciprocate common experiences of living with an SCI: “The best rehab information I received, or improvement in life I’ve had, was from talking to other guys who are disabled” (Patrick), and: “If [peers] weren't around then, and you would just struggle. [Parasports] wouldn't be very much fun and you wouldn't want to go back” (Eric). Learning and receiving guidance from peers, including how to engage in adapted physical activity, has supported participants’ physical activity maintenance.

### *Accessibility*

Accessibility, both physical and social, strongly supported participations physical activity maintenance. Participants identified the accessibility of the built environments of their physical activity spaces, and social inclusion and accessibility by community programs as highly important.

**Physical.** Participants expressed that physical activity is easier when environmental barriers remain low, and physical activity facilities are accessible for individuals living with SCI: “Yeah, having access to all those [facilities], again lowering those barriers, is going to increase access and participation and individuals being able to participate in sport or rec physical activity” (Andrew). It is also more inviting for individuals living with SCI to start and continue to be physically active when the built environment is accessible: “As long as there is *not* more barriers and burdens [within the environment] than benefits [experienced] from the exercise, they're going to want to come back” (Andrew).

**Social.** Socializing with people in an inclusive, equitable, socially safe environment experienced in adapted physical activity, promotes on-going physical activity engagement. The social accessibility can also be promoted through parasport as Patrick mentioned that parasport should not be reserved for people with SCI. His wheelchair rugby club involves people without disabilities, Invictus Games athletes, and Wounded Warrior athletes. The involvement of people without a disability enhances the sustainability of the program, but more importantly it provides learning opportunities for all members and helps create connections between people with and without a disability: “I think [parasport] is beneficial to anybody, disabled or not. Having a team, your involvement is very helpful” (Patrick). Patrick continued by suggesting that people without

disabilities engagement in parasport can be a way to educate people without disabilities about people with disabilities, while demonstrate a positive, inclusive social environment.

### ***Readiness***

An interesting commonality expressed by each participant was their interest and readiness to engage in physical activity after their injury. The time at which participants expressed a desire to return to physical activity was different for each participant. Scott and Andrew were both highly interested to be physically active shortly after their injury. They wanted to resume the familiarity of physical activity participation: “You have to put everything else aside and say ‘hey do I want to sit on the sidelines and think about my past’ or do I want to pull up my drawers, carry on, or to just keep going” (Scott). Patrick was interested in being active after his injury, but slowly integrated physical activity by means of work (i.e., summer camp, coaching rugby) or leisure activities. For Eric, he only had the interest and willingness to start being physically active during his second admission to rehabilitation. Therefore, participants’ readiness to engage in physical activity after their SCI may be an important factor to begin and maintain physical activity.

### ***Enjoyment***

Enjoyment of physical activity was a common theme across participants. They engage in their physical activity because they do derive some satisfaction from it. Their interest in and enjoyment of physical activity prior to their SCI seemed to be a driving factor in their current physical activity engagement. Each participant spoke of a love for a particular type of physical activity (e.g., parasport, handcycling). Some participants found that activity immediately (e.g., wheelchair rugby) while others needed to find activities outside of parasport. Overall, enjoyment was an important factor in their physical activity maintenance.

### Discussion

The purpose of this study was to explore physical activity maintenance among adults with SCI. The results of this study identified reasons as to *why* adults with SCI maintain their physical activity including, minimizing health risk, experiencing the benefits of physical activity towards their SCI self-care, a sense enjoyment from physical activity participation, and the gratification of the inclusive environment of parasport. Also, this study revealed the strategies as to *how* adults with SCI maintain their physical activity including, planning, having access to accessible facilities and community programs, and having the accountability of teammates or support from peers at parasport. Interventions within the current literature remains heavily focused on outcomes of short-term physical activity participation. This study addressed a call for further understanding of physical activity maintenance (Conner & Norman, 2017; Martin Ginis et al., 2016). The design and results of this study broadens the current scope of physical activity literature by contributing a focused understanding of physical activity maintenance among the adult SCI population.

The maintenance themes identified in the results of this study align with the five themes related to maintenance of a health behaviour proposed by Kwasnicka et al. (2016). The themes related to planning and prioritization, accessibility to physical activity facilities and community resources, and peer support, directly align with three of Kwasnicka et al. (2016) health behaviour maintenance themes; the need for strong self-monitoring techniques, plentiful physical and psychological resources, and supportive environments. The results suggest partial support of Kwasnicka et al. (2016) maintenance theme of maintenance is habitual or supported by autonomic cues. Participants did not explicitly state their physical activity maintenance as habitual, but participants did elaborate that the establishment of physical activity routine was

supportive of their physical activity maintenance. When discussing physical activity routines, participants had some difficulty removing themselves from, what they perceived as, their ordinary routine. Our conversations required more probes about why or how their physical activity engagement was so well established. The need to probe participants to verbalize reasons why and how they maintain their physical activity could suggest the habitual nature of their physical activity. Also, the results of this study are inconsistent with Kwasnicka et al. (2016) maintenance theme that a behaviour is more likely to be sustained if reinforcement is provided for immediate and affective outcomes, rather than long-term, rational outcomes. Our participants expressed realizing the long-term, rational outcomes of physical activity as an important factor to their maintenance (e.g., shoulder health, ease of transfers and mobility). However, participants' explanations of their enjoyment, passion, or love for physical activity suggest affective outcomes may support physical activity maintenance. Further inquiry about autonomic responses and relevant cues, as well as affective outcomes versus long-term outcomes, should occur to clarify if these theoretical concepts are relevant for physical activity maintenance among adults with SCI.

Although the results align with Kwasnicka et al. (2016) theoretical themes of health behaviour maintenance, the commonality between the physical activity adoption literature and the results of this maintenance study are evident. For the adult SCI population, social factors (i.e., social interaction, equitable participation, a sense of belonging), self-gratifying reasons (i.e., personal enjoyment, independence, health benefits), and motivational factors (i.e., high autonomous motivation, high self-efficacy) increase physical activity participation (Blauwet, 2019; Kerstin et al., 2006; Rocchi et al., 2017; van den Akker et al., 2019). Physical activity initiation intervention for adults with SCI also identified greater autonomous motivation, health participation, self-efficacy, and goal setting by participants in the intervention group compared to

a wait-list control group (Chemtob et al., 2019). Participants of this study reported similar reasons for their physical activity maintenance. All participants reported gratification from the social interactions and receiving peer support via adapted physical activity, returning to physical activity because of the on-going health benefits they receive, and their enjoyment, or intrinsic motivation for physical activity. The overlap between physical activity initiation and maintenance factors is significant because it validates that the variables identified for initiating physical activity among the SCI population also occurs for physical activity maintenance. Current physical activity interventions for adults with SCI should continue to foster these variables as they are also important for physical activity maintenance. However, future physical activity interventions need longer follow-up periods post-intervention to understand how to sustain these variables over time.

Participants described a direct awareness and recognition of the health benefits from their physical activity maintenance. Participants directly connected their ease in mobility, increase in strength for transferring, and reduction in health complications to their physical activity maintenance. Recognition of health improvements from physical activity maintenance has not been reported in physical activity initiation studies among adults with SCI. However, it has been reported in physical activity maintenance studies in other patient populations. Cardiac rehabilitation exercise maintainers have expressed clear connections between their physical activity participation and noticeable health improvements (Sweet et al., 2019). Also, cancer survivors who maintained their physical activity after completing cancer treatment reported reduced late and long-term effects from their cancer treatment and improvements in their health and physical functioning (Bulmer et al., 2012; Liska & Kolen, 2019; Livsey & Lewis, 2017; McDonough et al., 2008). Similarly, Amireault et al. (2012) reported individuals who are

satisfied with behavioural outcomes are more likely to maintain the behaviour. We are assuming that satisfaction with an expected outcome can imply the realization of the benefit of physical activity participation. However, understanding how to increase the realizations of the benefits of physical activity should be examined in future physical activity studies among adults with SCI. Possible avenues may include incorporating mindfulness activities such as audio recorded mindfulness techniques in bringing individuals attention to how their body feels while exercising. Utilizing such techniques could promote awareness of the benefits of physical activity engagement (Gillman & Bryan, 2019; Sala et al., 2021).

Participants spoke of the introduction to parasport during rehabilitation as being important in resuming their physical activity, and navigating daily life with an SCI. Participants voiced that parasport and adapted physical activity should become an integral part of rehabilitation because of the physical benefits of engaging in physical activity, psychosocial benefits of interacting with peers, and it serves as a vector for learning how to remain physically active upon discharge from rehabilitation. Despite all participants being introduced to parasport, they did not necessarily continue with the parasport that they were first introduced to during rehabilitation. Each participant engaged in a different frequency, intensity, duration, and type of physical activity. Some participants had a more leisure approach to their physical activity, whereas for other participants', physical activity was for competitive and structured reasons. They eventually found their preferred physical activity, demonstrating that for physical activity maintenance to occur, adults with SCI need to find a type of physical activity that is right for them.

When examining or encouraging physical activity adoption and maintenance, individual interests and differences should be at the forefront. Rehabilitation centers and community

organizations may need to consider introducing people with SCI to a variety of adapted physical activities that is in addition to traditional parasport. For example, our participants engaged in hand cycling, cross-country sit-skiing, and fitness since leaving rehabilitation. Other physical activity options that could be promoted are adapted sailing, rowing, and curling. Increased accessibility to physical activity opportunities and resources can allow for greater physical activity participation among adults with SCI, while also supporting the opportunity to learn SCI self-management from peers (Bonnell et al., 2021; Sakakibara et al., 2013). If community organizations were to provide a breadth of adapted physical activities and access to adapted physical activity equipment (e.g., equipment loan service), individual interest in a particular physical activity could promote physical activity adoption and maintenance.

Adults with SCI in this study were highly active prior to their injury and expressed an interest in resuming a familiar physical activity routine at some point after their injury. Engagement in previous physical activity, either structured interventions or unstructured participation, has been reported to aid in the development of continued physical activity engagement (Amireault et al., 2012). The frequent engagement, and mastery of physical activity pre-injury, likely helped participants to want to engage in physical activity after their injury. This may also have helped them to be psychologically ready to engage in physical activity after their SCI. Positive psychological responses have been associated with a higher return to sport and physical activity after a sport-related injury (Ardern et al., 2012). Athletes with less negative emotion and shift towards positive emotions such as confidence and readiness during rehabilitation, have a positive transition back to sport or physical activity participation (Ardern et al., 2012). Although the interest and readiness to resume physical activity was common across cases, participants' physical activity engagement prior to their injury is a limitation to this study.



Considering all participants had pre-injury physical activity experiences, it remains difficult to understand if the concept of psychological readiness would still apply to adults with SCI who were not active prior to their injury. Future research should include adults with SCI who initiated and maintained their physical activity after their SCI to examine if this concept of psychological readiness and the other themes identified in this study remain important for physical activity maintenance after a SCI.

Taken together, the themes of physical activity maintenance discussed could also tie into a new concept in disability studies, namely experiential aspects of participation, or quality participation (Martin Ginis et al., 2017). According to this framework, high quality participation is likely to occur when the concepts of autonomy (i.e., having independence, control), mastery (i.e., experiencing achievement), belongingness (i.e., acceptance and respect from others), challenge (i.e., feeling appropriately challenged), engagement (motivated; focused), and meaning (i.e., contributing towards obtaining a personal or socially meaningful goal) are experienced. Our participants' experiences can be directly and indirectly linked to these concepts. For instance, our participants' selection of their preferred physical activity demonstrated a sense of autonomy, their past experience with physical activity highlights mastery, and their focus on self-improvement and betterment as an athlete, ensure their activity is of an optimal challenge. The connection with peers aligns with belongingness while the ease of transferring and being mobile could have provided more meaning to their physical activity. Other sport and physical activity studies in the disability context found connections between quality participation and sport and physical activity participation (Allan et al., 2018; Shirazipour & Latimer-Cheung, 2020). For example, introduction to high quality adapted physical activity programs in rehabilitation, bonding and peer support from parasport involvement, and opportunities for competitive

parasport experiences, supported military veteran's physical activity maintenance (Shirazipour & Latimer-Cheung, 2020). As such, the findings from our study may support the tenet that higher quality participation can lead to sustained physical activity engagement. Future studies are needed to specifically explore this link in a physical activity maintenance and SCI domain.

### **Limitations**

Although the use of a multiple case study design for this study allowed for richness and depth in the collection of robust qualitative data, it is recognized that the responses and personal experiences were individualistic. As an accommodation for completing data collection remotely, participants were asked to provide physical activity diaries and photographs as an alternative to observations. The use of physical activity diaries and photographs illuminated further the perspective of physical activity maintenance of the participant, removing the possibility of documenting data from an outside perspective by observations. While both methods provide strength in understanding participants physical activity, additional perceptions from observations could have been valuable. Also, the descriptions within participants' physical activity diaries were not as detailed or rich as anticipated, removing additional insight that could have been contributed. Each case in this study was centered on a male participant with a traumatic SCI who used a manual wheelchair. The experiences of physical activity maintenance may be different for females living with a SCI, individuals living with non-traumatic SCI, or the use other mobility aids. Future research is warranted to explore the experiences of physical activity maintenance of a broader ranges of adults with SCI by using quantitative methodologies, or other qualitative methods.

**Conclusion**

Adults with SCI in this study shared how and why they maintain their physical activity participation. It appears that efforts to support physical activity maintenance need to focus on ensuring that adults with SCI enjoy their activities, learn how to plan their physical activity to establish a routine, have access to facilities and programs that are physically and socially safe, and have the opportunity to learn from peers. Further, strategies to help adults with SCI connect their physical activity participation to improvements in other life domains could also assist with physical activity maintenance. The results from this multiple case-study therefore provides novel insight and directions on how to continue to explore and promote physical activity maintenance in the adult SCI population.

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## Appendices

### APPENDIX A



**Research Ethics Board Office**  
James Administration Bldg.  
845 Sherbrooke Street West, Rm 325  
Montreal, QC H3A 0G4

Tel: (514) 398-6831

Website: [www.mcgill.ca/research/research/compliance/human/](http://www.mcgill.ca/research/research/compliance/human/)

#### **Research Ethics Board 2 Certificate of Ethical Acceptability of Research Involving Humans**

**REB File #:** 20-10-029

**Project Title:** Exploring Physical Activity Among Adults with Spinal Cord Injury

**Principal Investigator:** Tayah Liska

**Department:** Kinesiology and Physical Education

**Status:** Master's Students

**Supervisor:** Professor Shane Sweet

**Approval Period:** December 22, 2020 – December 21, 2021

The REB 2 reviewed and approved this project by delegated review in accordance with the requirements of the McGill University Policy on the Ethical Conduct of Research Involving Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.

Georgia Kalavritinos  
Ethics Review Administrator

- 
- \* Approval is granted only for the research and purposes described.
  - \* Modifications to the approved research must be reviewed and approved by the REB before they can be implemented.
  - \* A Request for Renewal form must be submitted before the above expiry date. Research cannot be conducted without a current ethics approval. Submit 2-3 weeks ahead of the expiry date.
  - \* When a project has been completed or terminated, a Study Closure form must be submitted.
  - \* Unanticipated issues that may increase the risk level to participants or that may have other ethical implications must be promptly reported to the REB. Serious adverse events experienced by a participant in conjunction with the research must be reported to the REB without delay.
  - \* The REB must be promptly notified of any new information that may affect the welfare or consent of participants.
  - \* The REB must be notified of any suspension or cancellation imposed by a funding agency or regulatory body that is related to this study.
  - \* The REB must be notified of any findings that may have ethical implications or may affect the decision of the REB.



**APPENDIX B****Screening Questions for Participation****Screening Questions:**

What is your age?

What year were you diagnosed with an SCI?

What year did you complete rehabilitation?

What type of mobility aid did you use?

What is the level of your injury?

Can you identify someone who promotes your on-going engagement in physical activity?

Approximately, how long have you been engaging in physical activity since completing rehabilitation (months/years)?

Please complete the following table (next page). The questions within the table ask about your weekly physical activity engagement.

Brief description of the intensity level	<b>Aerobic Activities</b> Activities that typically increase heart rate and breathing. These activities include but are not limited to sport.		<b>Strength Training</b> These exercises should work your major muscle groups. This includes exercises such as lifting weights or using elastic resistance bands.	
	In the past 7 days, how many days did you do cardiovascular activities corresponding to these three intensity levels?	How many minutes per day? * if the number of minutes differs from day to day, please indicate this	In the past 7 days, how many days did you do muscle building activities corresponding to these three intensity levels?	How many minutes per day? * if the number of minutes differs from day to day, please indicate this
<b>Mild intensity</b> Requires very light physical effort; mild intensity activities make you feel like you are working a little bit, but you can keep doing them for a long time without getting tired				
<b>Moderate Intensity</b> Requires some physical effort; moderate intensity activities make you feel like you are working somewhat hard, but you can keep doing them for a while without getting tired...				
<b>Vigorous Intensity</b> Requires a lot of physical effort. These activities make you feel like you are working really hard, almost at your maximum. You cannot do these activities for very long without getting tired. These activities may be exhausting.				

**Participant Consent Form – Adult with Spinal Cord Injury****REB#** \_\_\_\_\_

**Researcher:** Tayah Liska, MA student, McGill University, Department of Kinesiology and Physical Education, 613-983-3850, [tayah.liska@mail.mcgill.ca](mailto:tayah.liska@mail.mcgill.ca)

**Supervisor:** Shane N. Sweet, Ph.D., Associate Professor, Department of Kinesiology and Physical Education, McGill University, 514-398-4184 ext. 09903; [shane.sweet@mcgill.ca](mailto:shane.sweet@mcgill.ca)

**Co-investigators:** Haley Flaro, Executive Director, Ability New Brunswick; Emilie Michalovic, Ph.D. Candidate, McGill University.

**Title of Project:** Exploring Physical Activity Maintenance Among Adults with Spinal Cord Injury

**Sponsor(s):** Social Sciences and Humanities Research Council of Canada

***Purpose of the Study:***

As a researcher working in the area of health promotion, I am looking to understand and improve physical activity participation and associated well-being among adults living with spinal cord injury. This study aims at exploring how and why adults with spinal cord injury maintain their physical activity participation.

***Study Procedures:***

Participating in this study will involve the following steps:

1. We will begin with a preliminary interview, which will be an introduction and we will discuss your life experiences. The interview will take approximately one hour. This interview will be conducted over video call using Microsoft Teams. The video call will be recorded so the conversation can be transcribed afterwards. During the interview, the researcher will be in a quiet, private setting. It is recommended that you choose a quiet, private setting for the interview. You may keep your camera setting **off** if you are **not** comfortable showing yourself or your surroundings.
2. The researcher will conduct an interview with a person who you identify as promoting your continued participation in physical activity. The interview is meant to gain an additional understanding about this person's role towards promoting your continued participation to physical activity, as well as an additional perspective as to how and why you are continually active.
3. The researcher will collect your physical activity journals (written, video recorded, or audio recorded journal) documenting your physical activity experience and photographs you took of your physical activity environment. The information you provide to us will allow for additional points about why you continue to engage in your preferred means of physical activity during our second interview that will be conducted by the researcher. Digital equipment (voice recorder, digital camera, password protected smart phone with

camera recording capability) will be provided to you to take pictures of your physical activity environment and if you would prefer to digitally record your reflective physical activity journals. Notebooks will be provided if you prefer to handwrite your reflective physical activity journal

4. After the observation and preliminary interview, a second interview between the researcher and yourself. The second interview is meant to speak further as to how you continue to engage in physical activity while living with a spinal cord injury and why you choose to do so. This interview will be conducted over video call using Microsoft Teams. The video call will be recorded so the conversation can be transcribed afterwards. During the interview, the researcher will be in a quiet, private setting. It is recommended that you choose a quiet, private setting for the interview. You may keep your camera off if you are not comfortable showing yourself or surroundings during the interview.

***Voluntary Participation:***

Your participation in this study is voluntary. You may refuse to participate in any parts of the study, you may decline to answer any question, and you may withdraw from participating in the study any time during the data collection, for any reason. You may withdraw from the study up to seven years after the completion of data collection and analysis. If you decide to withdraw from the study, any information you have provided will be destroyed, unless you have given permission otherwise. Once data has been combined for publication, it may not be possible to withdraw your data from the publication in its entirety. It can only be removed from analysis and from use in future publications. Identifiable data will be kept for a minimum 7 years after the first publication of the main results. Your withdrawal from the study will have no impact on your membership with Ability New Brunswick and your access to the programs and services provided by Ability New Brunswick.

***Potential Risks:***

There are no anticipated harms or risks associated with the participating in this study. You may bring up some sensitive topics during the interview (e.g., mental health, physical injury), but these types of issues are not the purpose of the interview. If you feel you need to or want to discuss these types of issues with a professional, the researcher will refer you to the appropriate health professional. Although all precautions are taken, considering that data collection will be done through the internet, there is a possibility of information being intercepted by a third party when using communications through the internet.

***Potential Benefits:***

Participating in the study might not benefit you directly, but it will help the researcher to better understand your experiences and choice to continue to be physical active. This information could then lay the foundation for implementing improved recreation and physical activity programs for adults living with spinal cord injury. Also, your participation in this study can provide benefit to Ability New Brunswick for their understanding of what programs and services that their community members utilize that support their continued participation in physical activity. The information obtained from your participation in this study can assist Ability New Brunswick in future program development and service support to Ability New Brunswick members.

***Confidentiality:***

Any information that is obtained in connection with this study and that can be identified in connection with you, the participant, will remain confidential and will not be disclosed. You will be assigned a pseudonym (i.e., a fake name) to ensure your confidentiality. All of your data will be referred to by the pseudonym. Any identifiable information disclosed during the interviews (e.g., names, locations) will be removed from the transcripts. The pictures that have been taken will be used for data analysis. You have the right to choose how you would like these photos to be used, either for just data analysis or for both data analysis and presentations/publications of the results. Only Tayah Liska (principal investigator) and Prof. Shane N. Sweet (faculty supervisor) will have access to the identifiable data. Copies of the video recordings, photos, and reflective journals (written, audio recorded, or video recorded) will be stored on the researcher's individual computer. The computer is password-protected, and the recordings will be encrypted. She will use the video recordings, transcripts, reflective journals, and photos to analyze the data, to then write scientific articles and share the results in presentations or to community partners. Once data analysis is complete, photos, video files, and transcripts will be stored on a digital file, that is password protected, on the TIE Lab computer in Currie Gymnasium at McGill University. Your name will never be disclosed in any of these publications or presentations. Any pictures published or presented will not include your face or anybody else's face, and other identifiable features (such as birthmarks, scars, tattoos, and piercings) will be blurred in the pictures. Only general findings will be presented. The video recordings, photographs and transcripts will be transferred to McGill for data storage for a minimum period of 7 years.

***Honoraria:***

Each participant will be given a cash compensation of 25 CAD for their participation in each interview, for a total of \$50. Compensation will be provided after each interview.

***Questions:***

If you have any questions or would like clarifications about the study, please contact Tayah Liska, the researcher of the study.

Tayah Liska, McGill University, Department of Kinesiology and Physical Education, 514-398-4184 (extension 0481); [tayah.liska@mail.mcgill.ca](mailto:tayah.liska@mail.mcgill.ca)

Shane N. Sweet, McGill University, Department of Kinesiology and Physical Education, 514-398-4184 (extension 09903); [shane.sweet@mcgill.ca](mailto:shane.sweet@mcgill.ca)

**If you have any ethical concerns or complaints about your participation in this study, and want to speak with someone not on the research team, please contact the McGill Ethics Manager at (+1) 514-398-6831 or [lynda.mcneil@mcgill.ca](mailto:lynda.mcneil@mcgill.ca).**

***Consent to participate***

Please sign below if you have read the above information and consent to participate in this study. Agreeing to participate in this study does not waive any of your rights or release the researchers from their responsibilities. A copy of this consent form will be given to you and the researcher will keep a copy. Verbal consent can be provided and documented on this waiver if written/scanned copy/electronic signature/mailed consent is not possible.<sup>1</sup>

As part of the research study, you may be asked to take and share pictures of yourself and your surroundings. These photos could be used in presentations or be published if you agree. All

faces, including yours, will be blurred/covered if presented to maintain confidentiality. Please indicate your preference below:

1. I consent for the researcher to publish/present any pictures of my surroundings or myself. \_\_\_\_

Participant's Name: (please print) \_\_\_\_\_

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Interviewer's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**<sup>1</sup> Verbal Consent :**

[Participants name] \_\_\_\_\_ has provided verbal confirmation that they have read and understand the above information, are aware that agreeing to participate in this study does not waive any of their rights or release the researchers from their responsibilities, and consent to participate in this study. [Participants name] \_\_\_\_\_ has also verbally provided their choice of photography preference listed above and their selection has been marked and documented by the interviewer (Tayah Liska). The interviewers signature above indicates that verbal consent has been provided by the participant.



**Participant Consent Form – Identified Physical Activity Facilitator**  
**REB#** \_\_\_\_\_

**Researcher:** Tayah Liska, MA student, McGill University, Department of Kinesiology and Physical Education, 613-983-3850, [tayah.liska@mail.mcgill.ca](mailto:tayah.liska@mail.mcgill.ca)

**Supervisor:** Shane N. Sweet, Ph.D., Associate Professor, Department of Kinesiology and Physical Education, McGill University, 514-398-4184 ext. 09903; [shane.sweet@mcgill.ca](mailto:shane.sweet@mcgill.ca)

**Co-investigators:** Haley Flaro, Executive Director, Ability New Brunswick; Emilie Michalovic, Ph.D. Candidate, McGill University.

**Title of Project:** Exploring Physical Activity Maintenance Among Adults with Spinal Cord Injury

**Sponsor(s):** Social Sciences and Humanities Research Council of Canada

***Purpose of the Study:***

As a researcher working in the area of health promotion, I am looking to understand and improve physical activity participation and associated well-being among adults living with spinal cord injury. This study aims at exploring how and why adults with spinal cord injury maintain their physical activity participation.

***Study Procedures:***

Participating in this study will involve the following steps:

5. The researcher will conduct an interview with yourself, a person who has been identified by a person living with a spinal cord injury as promoting their continued participation in physical activity. The interview is meant to gain an additional understanding about an external role a person has towards promoting continued participation to physical activity for a person living with a spinal cord injury, as well as an additional perspective as to how and why that person is continually active. This interview will be conducted over video call using Microsoft Teams. The interview will take approximately one hour. The video call will be recorded so the conversation can be transcribed afterwards. During the interview, the researcher will be in a quiet, private setting. It is recommended that you choose a quiet, private setting for the interview. Or, you may keep your camera setting **off** if you are **not** comfortable showing yourself or surroundings.

***Voluntary Participation:***

Your participation in this study is voluntary. You may refuse to participate in any parts of the study, you may decline to answer any question, and you may withdraw from participating in the study at any time during the data collection, for any reason. You may withdraw from the study

up to seven years after the completion of data collection and analysis. If you decide to withdraw from the study, any information you have provided will be destroyed, unless you have given permission otherwise. Once data has been combined for publication, it may not be possible to withdraw your data in its entirety. It can only be removed from analysis and from use in future publications. Identifiable data will be kept for a minimum 7 years after the first publication of the main results.

***Potential Risks:***

There are no anticipated harms or risks associated with the participating in this study. You may bring up some sensitive topics during the interview (e.g., mental health, physical injury), but these types of issues are not the purpose of the interview. If you feel you need to or want to discuss these types of issues with a professional, the researcher will refer you to the appropriate health professional. Although all precautions are taken, considering that the data collection will be done through the internet, there is a possibility of information being intercepted by a third party when using communications through the internet.

***Potential Benefits:***

Participating in the study might not benefit you directly, but it will help the researcher to better understand your experiences and choice to continue to be physical active. This information could then lay the foundation for implementing improved recreation and physical activity programs for adults living with spinal cord injury.

***Confidentiality:***

Any information that is obtained in connection with this study and that can be identified in connection with you, the participant, will remain confidential and will not be disclosed. You will be assigned a pseudonym (i.e., a fake name) to ensure your confidentiality. All of your data will be referred to by the pseudonym. Any identifiable information disclosed during the interviews (e.g., names, locations) will be removed from the transcripts. Only Tayah Liska (principal investigator) and Prof. Shane N. Sweet (faculty supervisor) will have access to the identifiable data. Copies of the video recordings will be stored on the researcher's individual computer. The computer is password-protected, and the recordings will be encrypted. She will use the video recordings and transcripts to analyze the data, to then write scientific articles and share the results in presentations or community partners. Once data analysis is complete, photos, video files, and transcriptions will be stored on a digital file, that is password protected, on the TIE Lab computer in Currie Gymnasium. Your name will never be disclosed in any of these publications or presentations. Only general findings will be presented. The video recordings and transcripts will be deleted and transferred to the McGill data storage system for a minimum period of 7 years.

***Honoraria:***

Each participant will be given a cash compensation of 25 CAD for their participation in the interview. Compensation will be provided after the interview.

***Questions:***

If you have any questions or would like clarifications about the study, please contact Tayah Liska, the researcher of the study.

Tayah Liska, McGill University, Department of Kinesiology and Physical Education, 514-398-



4184 (extension 0481); [tayah.liska@mail.mcgill.ca](mailto:tayah.liska@mail.mcgill.ca)

Shane N. Sweet, McGill University, Department of Kinesiology and Physical Education, 514-398- 4184 (extension 09903); [Shane.Sweet@mail.mcgill.ca](mailto:Shane.Sweet@mail.mcgill.ca)

**If you have any ethical concerns or complaints about your participation in this study, and want to speak with someone not on the research team, please contact the McGill Ethics Manager at (+1) 514-398-6831 or [lynda.mcneil@mcgill.ca](mailto:lynda.mcneil@mcgill.ca).**

***Consent to participate***

Please sign below if you have read the above information and consent to participate in this study. Agreeing to participate in this study does not waive any of your rights or release the researchers from their responsibilities. A copy of this consent form will be given to you and the researcher will keep a copy. Verbal consent can be provided and documented on this waiver if written/scanned copy/electronic signature/mailed consent is not possible.<sup>1</sup>

Participant's Name: (please print) \_\_\_\_\_

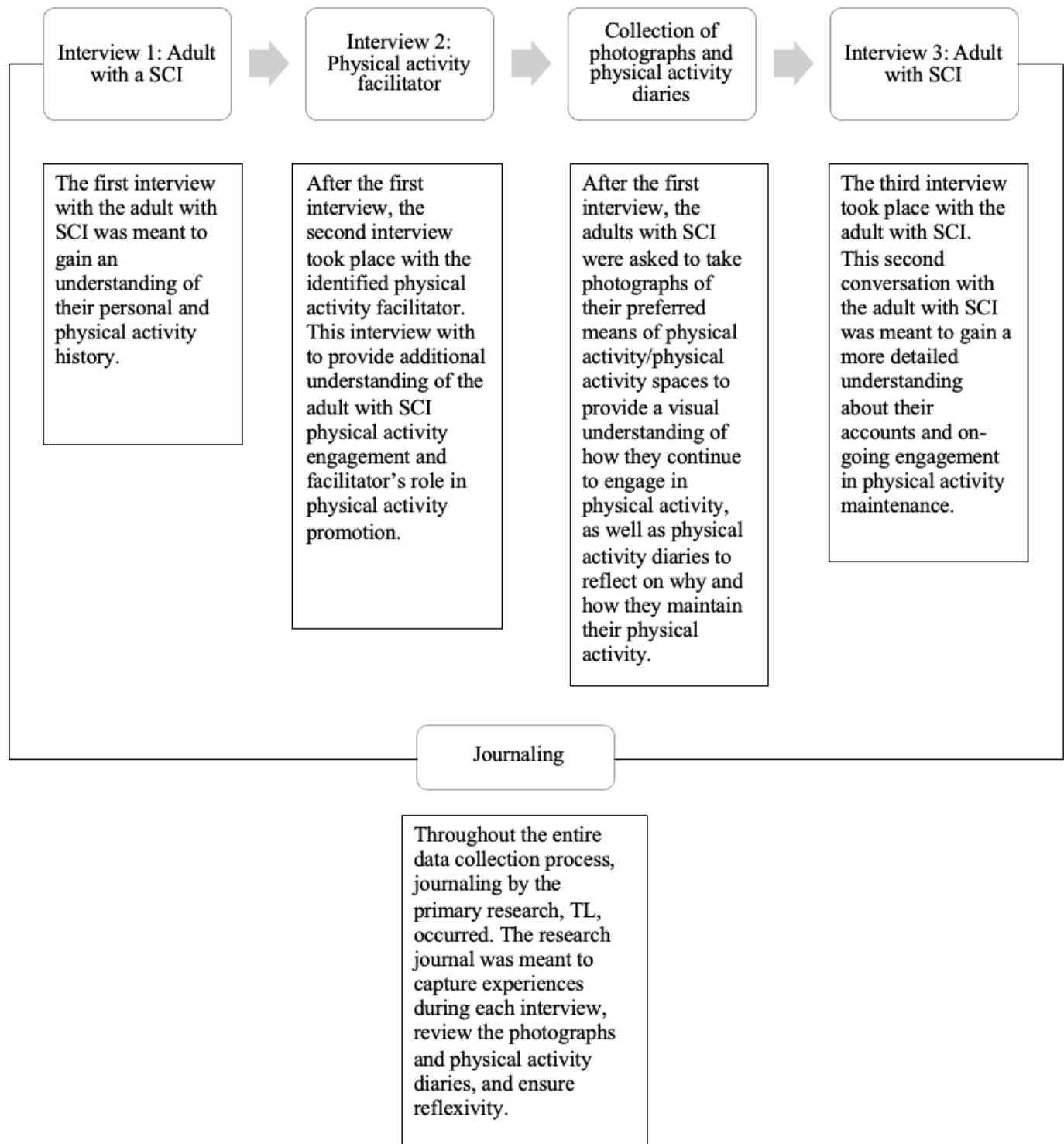
Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Interviewer's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**<sup>1</sup> Verbal Consent:**

[Participant's name] \_\_\_\_\_ has provided verbal confirmation that they have read and understand the above information, are aware that agreeing to participate in this study does not waive any of their rights or release the researchers from their responsibilities, and consent to participate in this study. The interviewer's signature above indicates that verbal consent has been provided by the participant.

## APPENDIX E

**The Process and Descriptions of the Stages of Data Collection**

**APPENDIX F****Interview Guide: Participant with Spinal Cord Injury**

1. Tell me about yourself (How would you describe yourself to a stranger?)

2. What has been your journey since your SCI?

Probe: SCI diagnosis and rehabilitation experiences

Probe: Impact on you (physically, mentally, emotionally) and daily life (routines, hobbies, activities)

3. To get a sense of your physical activity history, describe your physical activity participation from when you first remember to now?

Probe: Activity types, frequency, duration, structured/unstructured prior to SCI

Probe: Activity types, frequency, duration, structured/unstructured during rehabilitation

Probe: Activity types, frequency, duration, structured/unstructured since rehabilitation

Probe: Has your physical activity changed or been impacted (if at all) since your injury?

4. Why have you continued to participate in physical activity?

Probe: Why is being physically active important to you?

5. What helps you to be able to continue to be active?

Probe: Social network, such as your family support and relationship with friends

Probe: Are the strategies you use now to help you remain active the same or different from before your SCI? Are the same or different since rehabilitation?

**APPENDIX G****Interview Guide: Identified Physical Activity Facilitator Participant**

1. How would you describe your relationship with \_\_\_\_?

2. What characteristics would you use to describe \_\_\_\_?

Probe: how did they managed with their injury? (if they knew them prior to SCI)

3. What are your physical activity interactions with \_\_\_\_?

Probe: What do you do to encourage \_\_\_\_ continue to engage in physical activity?

Probe: What do you believe is your role in helping \_\_\_\_ continue to be active?

4. What do you think drives \_\_\_\_ to participate in physical activity?

Probe: Why do you think that being physical active is important to \_\_\_\_?

5. What do you think keeps them going?

Probe: What do you think your role is to encourage them to continue to be active?

Probe: What do they do or what strategies do they use to help them remain active?

**APPENDIX H****Interview Guide: Second Interview with Participant with Spinal Cord Injury**

1. Since our last interview, what other reflections have you had about your physical activity and how you are able to maintain it?

2. What are some of the factors that help you maintain your physical activity?

Probe: Can you describe why these factors are important or helpful for you in maintaining your physical activity participation.

Probe: Are these factors for maintaining your physical activity internally or externally driven?

Probe: How else might these factors, or other reasons, help you continue to engage in physical activity on a regular basis.

3. I noticed in the observation period (\* COVID-19 procedure; journals/photographs sent to me) that \_\_\_\_\_? How does that impact your ability to continue to be active?

4. In our previous interview you mention \_\_\_\_\_ in regards to your physical activity participation? How does that help (or not help) your on-going physical activity participation?

5. [Facilitators Name] mention in their interview that you demonstrate [list specific attribute]. Would you consider this a characteristic that assist in your physical activity maintenance?

Probe: Would you describe this characteristic being more present during your physical activity to keep you going, Or, would they be present when you are not engaging in physical activity, but help you return to your activity?