THE EFFECTS OF KNOWLEDGE TRANSLATION THROUGH PEER VERSUS STUDENT TRAINERS ON EXERCISE SELF-EFFICACY AND PHYSICAL ACTIVITY LEVELS IN PEOPLE WITH SPINAL CORD INJURY

by

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Abstract

Background: A spinal cord injury (SCI), results in a myriad of serious secondary health complications including cardiovascular disease, obesity, and pressure sores due to immobility. These health conditions could be reduced by improving fitness and mobility by participation in physical activity (PA) and exercise. However the SCI population has been found to have the lowest levels of PA when compared to the general population. The reasons for this have been attributed to the many extrinsic barriers that those living with an SCI face daily, including cost, transportation, and lack of adapted equipment or facilities. In May 2013, the Physical Activity Research Centre (PARC) at ICORD opened its doors in an effort to reduce the extrinsic barriers, however, this did not address the many intrinsic barriers to exercise participation, including lack of motivation, time, and knowledge about where or how to exercise. Previous studies have indicated that the preferred messenger for the delivery of PA knowledge includes peers, and health service providers. Here, our goal was to investigate whether peers can change PA behaviour and bring this knowledge to action.

Methods: In this pilot randomized controlled trial, ten individuals with a SCI were randomly assigned to meet with a peer or student trainer (control) to discuss the PA guidelines for SCI. After the initial intervention, we investigated the effectiveness of peer trainers, compared to student trainers, to translate the PA guidelines to a SCI participant. We then instructed participants to meet with their peer/student trainer as desired for the remainder of the 3-month study. Exercise self-efficacy and overall PA levels were compared between baseline, week 1 and week 12. During an exit interview we explored the effect on intrinsic barriers to exercise along with participant satisfaction with the study.

Results: Overall no statistically significant findings were detected between groups, however nearly all participants scored well on knowledge acquisition and are now meeting the recommended PA guidelines.

Conclusion: Our findings suggest that student trainers could be as effective as peer trainers as it relates to overcoming intrinsic barriers and increasing overall PA within the SCI population.

Preface

All data contained in this thesis were collected by J. Megan Brousseau at the Physical Activity Research Centre (PARC) within the Blusson Spinal Cord Centre, Vancouver, BC. Methodologies were reviewed and approved by the UBC Clinical Research Ethics Board (#H16-00030).

The study contained in this thesis was not submitted for publication at the time of thesis submission.

I was the lead investigator on the project, responsible for concept development, study design, data collection and analysis, and manuscript composition. Dr. Guy Faulkner and Dr. Chris McBride were involved in concept development. Dr. Tania Lam was the supervisory author on the project and was involved in concept formation, study design, and thesis revisions.

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PARC – Physical Activity Research Centre

SCI – Spinal Cord Injury

ESES – Exercise self-efficacy scale

PA – Physical activity

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Dedication

I dedicate this thesis to my family, my friends, and my partner, and to Phoenix, who taught me to rise from the ashes. I love you all more than you know.

Chapter 1: Introduction

It is estimated that there are approximately 86,000 Canadians currently living with a spinal cord injury (SCI), with more than 4000 new cases reported each year (Noonan et al., 2012). A SCI can result in a loss of mobility with approximately 80% of people remaining dependent on a wheelchair for the rest of their lives (Post, de Witte, van Asbeck, van Dijk & Schrijvers, 1998). Along with paralysis, a disruption in sensation and cardiovascular regulation can lead to an inactive, sedentary lifestyle. This hypo-activity leads to a myriad of secondary health complications and chronic disease (Ashe, Craven & Krassioukov, 2006; Warburton, Sproule & Krassioukov, 2006), including cardiovascular disease, physical deconditioning and a lowered quality of life (Garshick et al., 2005; Noreau & Shephard, 1995). Participating in exercise and physical activity (PA) is the best defense against these secondary health conditions (Latimer-Cheung et al., 2013). However, people in wheelchairs often face several intrinsic and extrinsic barriers when trying to access physical activity, such as lack of information or knowledge, lack of accessible facilities and equipment, and lack of motivation (Scelza, Kalpakjian, Zemper & Tate, 2005). Many of these extrinsic barriers have been addressed with specialized facilities for SCI (e.g. PARC, MacWheelers) and the development of SCI specific PA guidelines (Ginis et al., 2011). Unfortunately, current data indicates that the SCI population is still not meeting the recommended guidelines for physical activity (Alghamdi et al., 2015). It seems the availability of SCI specific facilities and guidelines are not sufficient in addressing the intrinsic barriers to PA. We propose to target these intrinsic barriers, which include lack of motivation and knowledge, through the use of peer trainers to translate the PA guidelines while providing individualized social support in order to improve exercise self-efficacy and therefore exercise participation levels. Using the knowledge translation (KT) framework designed by

Graham et al. (2006) we aim to translate these guidelines to PA peer trainers who will, in turn, disseminate this knowledge to others, increasing exercise self-efficacy in the SCI participants, thereby mediating the behaviour of PA participation.

1.1 Impact of spinal cord injury

A spinal cord injury (SCI) refers to damage to the spinal cord resulting in a loss of sensory, motor and/or autonomic function below the level of the injury. A SCI can result from a direct trauma (e.g. car or diving accident, fall) or a non-traumatic event (e.g. congenital disease or tumor). The type and amount of damage to the spinal cord will affect both the level and the completeness of the injury causing a unique result in each individual with a SCI. If the damage affects either the thoracic, lumbar or sacral (T1-L5) regions of the spine, the individual is considered paraplegic and maintains the use of their arms and possibly some of their trunk. Should the damage occur within the cervical region of the spine (C1-C7) then the individual is considered tetraplegic, resulting in a loss or impairment in the arms, trunk, and legs. Depending on the level and completeness of the injury, sensorimotor and autonomic innervation between the brain and the body will be disrupted below the level of the lesion. This disruption, if above the spinal level of T6, could include sympathetic nervous system dysfunction as well. Disruption of the autonomic system results in resting hypotension, circulatory deregulation and can affect both cardiac and body temperature control (Nash, 2005). This functional and homeostatic decline leads to an even greater inactive lifestyle, physical deconditioning and sedentary-related illnesses (Nash, 2005). These illnesses include cardiovascular disease, bone and muscle atrophy, pressure ulcers, obesity, type II diabetes, and osteoporosis due to immobility (Garshick et al., 2005), exacerbating many psychosocial concerns including depression, stress and a lower quality of life

(Noreau & Shephard, 1995). With two of the leading causes of death for those who survive a SCI being coronary artery disease and suicide due to depressive disorders, there is increased interest in modifiable risk factors such as physical activity and exercise (Hicks et al., 2003). Indeed, there is increasing evidence of the impact of exercise and physical activity on cardiovascular health, musculoskeletal health, pain and psychosocial health and well-being in people with SCI (Wolf et al., 2010; Giangregoria & McCartney, 2006; Segatore, 1994; Nash, 2005; Teasell et al., 2010; Tawashy, Eng, Lin, Tang & Hung, 2009; Hicks et al., 2003).

1.2 Impact of physical activity on SCI

Research has shown that participating in regular physical activity (PA) is a mediating factor for preventing obesity (Albright et al., 2000; Grundy et al., 1999; Hamilton et al., 2008), decreasing the risks for obesity related illnesses (Allison et al, 1999; Lee & Skerrett, 2001), including coronary heart disease (Manson et al., 1999), hypertension and type II diabetes (Albright et al., 2000; Grundy et al., 1999), as well as many types of cancer (Lee, 2003) in the general population. Although there is somewhat less evidence evaluating the effects of exercise on specialized populations, such as persons with a SCI (Ginis et al., 2008), these benefits have also been shown in seniors, youth, cancer survivors, AIDS/HIV, obesity/diabetes and stroke survivors (Chodzko-Zajko et al., 2009; Janssen & LeBlanc, 2010; Schmitz et al., 2005; Smith et al., 2001; Hamilton et al., 2008; Ouellette et al., 2004). Physical activity (PA) has consistently been identified as an important mitigating factor for reducing the risks of morbidity and mortality (McAuley & Jacobson, 1991). Habitual PA decreases both risk and onset of diabetes and cardiovascular disease in the general population (Bassuk & Manson, 2005; Brien & Katzmarzyk, 2006) as well as in SCI (Buchholz et al., 2009). In fact, leisure time physical activity, defined as a physical activity that one chooses to do in their free time, such as exercising at a gym or playing sports, has been associated with a 30-50% reduction in the risk of type 2 diabetes and cardiovascular disease in SCI (Bussuk & Manson, 2005; Buchholz et al., 2009). It is also linked to improving musculoskeletal health, psychosocial health, and offers an alternate option to pharmaceutical pain-relief (Giangregoria & McCartney, 2006; Segatore, 1994; Nash, 2005; Teasell et al., 2010; Tawashy et al., 2009; Hicks et al., 2003).

1.2.1 Cardiovascular health

Due to the deficits in mobility as well as cardiovascular control caused by a SCI, it should come as no surprise that a significant cause of deaths among people with SCI can be attributed to major secondary complications such as cardiovascular disease. Although the risks for cardiovascular disease (CVD) are similar to that of an aging individual without an SCI, CVD occurs at an accelerated rate in the SCI population (Nash, 2005). The prevalence of cardiovascular disease in SCI can range upwards of 50% compared to 10% in an age-matched able-bodied population (Myers, Lee, & Kiratli, 2007). The probability of suffering from heart disease is four times more likely in the SCI population compared to individuals without a SCI (Cragg, Noonen, Krassioukov, & Borisoff, 2013). Cardiovascular disease has also been found to be the cause of over 40% of deaths among persons who have survived a SCI (Nash, 2005). Given the sedentary lifestyle, lack of mobility and possible disruption of the sympathetic nervous system (depending on spinal lesion level), resting heart rates and mean arterial pressures are often low which can also be linked to cardiovascular disease (Cowan & Nash, 2010). Physical activity is one of the best defenses against obesity and other precursors to cardiovascular diseases, as it lowers the body mass index (BMI) and waist circumference in individuals with SCI (factors contributing to both) (Buchholz et al., 2012) and can prevent the development of type II diabetes (Bauman & Spungen, 2000). Obesity is 2.5 times more evident among individuals with lower extremity disabilities than among those without any disability. Obesity can also exacerbate problems associated with disability, such as limited ambulation, difficulty with transfers, risk of pressure sores, psychological morbidity, and possible complications during surgery (Weil et. al, 2002). It has been found that 56% of SCI participants during rehabilitation are obese (BMI>22), a number that rises to 70% after discharge (de Groot et al., 2010). Everyday physical activity seems to have an important role in the fitness and health of persons within 1 year of a SCI, with higher physical activity levels correlating to lower risk of cardiovascular disease (Nooijen, 2012).

1.2.2 Musculoskeletal health

Disuse of muscles due to chronic paralysis leads to a reduction in muscle fiber numbers, which leads to muscle atrophy along with an eventual change in muscle fiber type (Round, Barr, Moffat, & Jones, 1993). Magnetic resonance imaging of the leg and thigh of SCI patients 24 weeks after injury revealed that the average cross-sectional muscle area was 45-80% lower of that of age- and weight-matched controls (Castro, Apple, Hillegrass, & Dudley, 1999), Similarly, Round et al. (1993), found that the muscle fiber composition of 70% of subjects with complete SCI were almost all, if not all, the more fatigable Type 2 muscle fiber type. Those who had some preservation of Type 1 fibers were paralyzed for the least amount of time among subjects and the proportion was still well below normal range. These results suggest that the loss of Type 1 fibers occurs early, with the loss of voluntary movement (Round et al., 1993). This loss of muscle function directly relates to demineralization and bone degeneration due to a lack of mechanical loading on the bones (Jiang, Dai, & Jiang, 2006). In fact, the bone mineral density in people with complete SCI has been found to decrease by 40-70% of normal values 2 years post injury

(Biering-Sorensen, Bohr, & Schaadt, 1990). Post injury osteopenia and bone fractures below the level of injury have been reported to occur in at least 21% of patients within the first year after SCI (Giangregoria & McCartney, 2006; Segatore, 1995; Nash, 2005). Physical activity and weight-bearing techniques have been found to improve muscle strength, as well as slow bone loss and reduce the risk of fracture (Mohr et al., 1997, Leeds, Klose, Ganz, Serafini, & Green, 1990, Hangartner, Rodgers, Glaser, & Barre, 1994).

1.2.3 Pain

Pain has often been found to be the source of a decreased quality of life post SCI along with a negative impact on function, participation in activities of daily living, and community reintegration (Teasall et al., 2010). Chronic pain can sometimes exceed the impact of other secondary consequences of SCI (Finnerup, 2013). Up to 37% of people with SCI rate the relief of pain as more important than the possibility of a cure of bowel and bladder function, which is understandable when 25% of pain sufferers have rated their pain as severe to extreme (Nepomuceno, Fine, & Richards, 1979). In a longitudinal study examining the prevalence and severity of pain associated with living with a SCI, including musculoskeletal, visceral and neuropathic pain, 81% reported a presence of pain (Siddall, McClelland, Rutkowski, & Cousins, 2003). A systematic review found the prevalence may be as high as 86% (Teasall et al., 2010). Although pain-reducing medications are the first line of treatment, it has been shown that chronic pain after SCI is not well managed by medical treatment, compounded by patient non-compliance or fear of drug-dependence (Finnerup, 2013; Teasall et al., 2010). Several studies looking at the impact of physical activity have found that long-term, twice-weekly exercise can significantly reduce pain levels (Hicks et al., 2003, Ginis et al., 2003; Tawashy et al., 2009).

1.2.4 Psychosocial health

The psychosocial effects of living with a SCI include depression, stress, decreased quality of life, diminished independence, reduced community involvement and overall life dissatisfaction (Hicks et al., 2003). It is not surprising that SCI, and the innumerable life adjustments that come with it, brings the occurrence of depressive symptoms (Orenszuk, Slivinski, Mehta, & Teasall, 2010). These challenges are placed not only on the individual but also on the family or caregivers. Indeed, Dreer et al., (2007) found that 15% of caregivers also reported major depressive disorders and emotional challenges. When compared to non-disabled controls, Kraus, Kemp, & Coker (2000) found that 42% of individuals with SCI reported depression, with 21% considered major depression. In fact, psychological morbidity was found in 30% of people with SCI, 2 years post injury (Craig, Hancock, & Dickson, 1994). Moreover, in a 6-year follow-up study, 29% of patients were still being treated for depression following their traumatic SCI (Orenszuk et al., 2010). Physical activity and exercise is a modifiable risk factor and has been shown in multiple studies to have a positive impact and a direct correlation in reducing these concerns (Hicks et al., 2003; Ginis et al., 2003; Tawashy et al., 2009). In a randomized controlled trial examining the effects of exercise in people with SCI, one group performed strength training and arm ergometry twice per week for 9 months compared to a control group who did not. As expected, the exercisers reported less stress, fewer depressive symptoms and greater life satisfaction compared to their matched controls (Hicks et al., 2003). These results were clear within 3 months of the study and sustained throughout. A follow-up study looked at the continuation of exercise and the continued psychosocial benefits with the same participants and found that there was a significant decrease in adherence to exercise 3 months post study (Ditor et al., 2003). These findings underline the importance of maintaining PA in order to sustain psychological well-being over the long-term.

These serious secondary health conditions not only have a major impact on the person but also have a substantial cost associated to them. In fact, the average cost of the initial year of hospitalization and rehabilitation in Canada averages 0.5-1 million dollars, but this number swells to 1.6-3 million per person per year thereafter, resulting in a staggering economic burden of 2.67 billion dollars annually (Krueger, Noonan, Trenamen, Joshi, & Rivers, 2013). By participating in regular physical activity and exercise, these risks are not only being mitigated, but improvements in function, independence and psychosocial health can be sustained.

In 2011, an expert panel released evidence-informed exercise guidelines for people living with SCI (Ginis et al., 2011). The guidelines were developed by an expert panel who conducted a systematic review of the literature and an implementation trial with stakeholders (practitioners working with SCI and individuals with SCI). Through this process, the expert panel determined the intensity, duration, and type of training required to generate fitness benefits among people with SCI (ages 18-64). The recommended guidelines, aimed at improving muscle strength and cardiovascular health, suggested that adults with SCI should be engaging in at least 20 minutes of moderate to vigorous intensity aerobic activity twice a week. Resistance training exercises were recommended twice a week, performing 3 sets of 8-10 reps for each major muscle group (Ginis et al., 2011).

1.3 Barriers

It is evident that PA can positively impact many of the physical and psychosocial secondary health concerns in the SCI population. Unfortunately, the SCI population has been found to have the lowest levels of PA when compared to the general population (Fernhall, Heffernan, Jae, & Hedrick, 2008). Although over 70% of people with SCI expressed that they were interested in participating in an exercise program, less than half were currently active (Scelza et al., 2005). Loss of mobility, pain, decreased strength, compromised bone health, hypotension and psychosocial factors are many of the obstacles deterring participation in physical activity and exercise. Ironically, these are also the issues most positively influenced by physical activity (Tawashy et al., 2009). Aside from an altered physiology and functional ability, many other challenges impede those with SCI when attempting to engage in physical activity (Fernhall et al., 2008). Reported barriers to physical activity and exercise among people living with SCI can be categorized into either intrinsic or extrinsic barriers (Scelza et al., 2005; Ginis et al., 2010; Kinne, 1999).

1.3.1 Extrinsic barriers

Extrinsic barriers have been identified as a lack of accessible equipment or facilities, including structural/architectural barriers such as the design of an exercise facility or the equipment within it. It also includes a lack of knowledge or awareness among the trainers or staff within the community centres (Scelza et al., 2005). When evaluating the accessibility of health clubs in both urban and suburban regions in the US, Rimmer, Wiley, Wang, & Rauworth, (2005) found that less than 50% had accessible routes or curb cuts and less than 10% had wheelchair accessible equipment available. It was also reported that less than 25% of health clubs had accessible doors, bathrooms or parking (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004), or an environment that could accommodate maneuvering a wheelchair (Rimmer et al., 2005). More recently, Arbour & Ginis (2011) found that out of 44 private for-profit, non-profit and public fitness and recreational facilities in urban areas, not one was completely accessible. Fortunately, many of these barriers are being addressed with the opening and operation of several specialized accessible exercise facilities in major city centres in Canada. Examples of these include MacWheelers at McMaster University (https://pace.mcmaster.ca/programs/mac-wheelers), the Steadward Centre at University of Alberta (http://www.steadwardcentre.org/), and most recently the PARC at ICORD at the University of British Columbia (http://icord.org/parc/). These centres are not only accessible and inclusive but also offer highly skilled staff with the knowledge and awareness of both the functional limitations and the potential complications (e.g. pressure ulcers or autonomic dysreflexia) of those with a SCI. Furthermore, they offer state-of-the-art equipment and options for exercise such as neuromuscular and functional electrical stimulation, hand game cycles and ergometers, seated ellipticals, body weight support systems, and standing frames, addressing many of the reported extrinsic barriers.

1.3.2 Intrinsic barriers

Intrinsic barriers are the intrapersonal factors that could interfere with exercise participation, including emotional/psychological factors, as well as knowledge/informational, education and training (Rimmer et al., 2004). Evidence suggests that these barriers can often vary based on age, gender, attitude, injury level and family support (Levins, Redenbach, & Dyck, 2004). However, among a group of 72 subjects with a SCI injury at C5 and below, which included a range of varying ages, genders, ethnicity, education, injury level and marital status, over 57% reported lack of motivation as their main concern (Scelza et al., 2005). Lack of information or knowledge was also a key barrier to over 38% of those who were surveyed (Scelza et al., 2005). Kinne et al. (1999) found that the most powerful predictors of exercise adherence for people with mobility impairments were motivation and exercise self-efficacy, and that these factors, if compromised, posed even greater barriers than the extrinsic environmental or structural barriers. It is important to note that engaging in physical activity is a behaviour and therefore when using a theory or framework, it is imperative to design an intervention that focuses on a variable that effects the change in behaviour and not the behaviour itself (Hansen & McNeal Jr., 1996). Indeed, in an analysis of behavioural interventions for promoting physical activity it was found that although behavioural intervention theories were applied, the mediating variable affecting this behaviour was not considered or evaluated and thus a substantial amount of these studies had little or no impact (Baranowski, Anderson, and Carmack, 1998).

1.4 Exercise behaviour and self-efficacy

Self-efficacy can play a critical role in how people think, feel and behave as they approach goals, tasks or challenges (Bandura 1977, 1986, 1997). Self-efficacy also reflects the confidence over one’s own motivation and is a major determinant in changing attitudes and behaviours towards physical activity and exercise participation (McAuley & Blissmer, 2000). With lack of motivation being the number one barrier to exercise, not only for SCI but also the able-bodied population (Scelza et al., 2005), it is not surprising that self-efficacy is considered one of the key variables in behavioural changes. When considering the promotion of physical activity in adults with physical disabilities, the most commonly used psychosocial theoretical frameworks that have been considered include the transtheoretical model, the theory of planned behaviour, and social cognitive theory (Burbank, Riebe, Padula, &Nigg, 2002; Kinne et al., 1999; Ginis et al., 2011). The transtheoretical model is based on 5 stages and is noted for providing helpful frameworks for understanding chronic behavioural risk factors such as sedentary lifestyles, addictions and diets. These stages have been identified as precontemplation, contemplation, preparation, action and maintenance (Prochaska & Velicer, 1997). When this model is applied to exercise behaviour it has been the most effective in the stage of precontemplation and uses the central concept of self-efficacy to influence choice, thoughts and an individual’s degree of confidence (Prochaska & Marcus, 1994). The theory of planned behaviour is based on connecting beliefs and behaviour focusing on perceived behavioural control. It is known to be an extension from the theory of reasoned action by adding perceived behavioural control which originates from self-efficacy theory (Armitage & Conner, 2001; Terry & O’Leary, 1995). The social cognitive theory states that through the observation of others performing a behaviour and the consequences of that behaviour, an individual will replicate the behaviour (Burbank et al., 2002). Social support is posited as the key influence of physical activity participation, but not without direct influence through the tenet of self-efficacy (Ginis et al., 2011). Bandura also realized that one’s own conviction and confidence in their ability to perform that behaviour is the most important precondition for behavioural change (Bandura, 1994). The common construct found in these frameworks and others are that they are fundamentally based on self-efficacy, an intrinsic determinant of exercise behaviour. Although the theoretical frameworks situating self-efficacy in behavioural change concepts have been extensively discussed in the literature, most previous and current studies looking at the variables that are mediating the changes in physical activity behaviour in people with SCI tend to investigate self-efficacy as a correlate (Kroll et al., 2017). Moreover, the effective components of the chosen theory or framework used in an intervention is often left unidentified (Baranowski et al., 1998).

1.4.1 Exercise self-efficacy

Research has shown a strong relationship between self-efficacy and exercise adherence in the general population (McAuley, Courneya, Rudolph, & Lox, 1994), patients with coronary heart disease (Robertson & Keller, 1992), older adults (McAuley, 1993), adult females (McAuley & Jacobson, 1991), along with many others (e.g. stroke, HIV, pregnancy, immigrants). Interestingly, the body of research suggests that self-efficacy can be both a determinant of PA behaviour as well as a consequence of PA participation, meaning that by building one's self-efficacy, one will in turn see an increase in PA participation. In a study looking at exercise behaviour as it relates to instructor influence, self-efficacy, self-motivation, and body composition, self-efficacy was the only significant predictor of overall exercise levels (McAuley & Jacobson, 1991). A later study evaluating the influence of self-efficacy along with other physiological and behavioural parameters found that self-efficacy was the most significant predictor of exercise adherence (McAuley, 1993). Also, a two-year randomized trial found that people who hold high self-efficacy beliefs prior to starting an exercise program show better adherence to an exercise regimen once implemented (Oman & King, 1998).

Self-efficacy has such an integral impact on exercise behaviour that it has been integrated into a valid and reliable method of measuring exercise self-efficacy in the Self-Efficacy for Exercise (SEE) scale (Resnick & Jenkins, 2000). This scale is a 13-item instrument focusing on self-efficacy expectations and the barriers to exercise affecting the ability to continue exercising (Resnick & Jenkins, 2000). Despite self-efficacy being one of the most widely researched concepts in health promotion, it was not until 2007 that the SEE was adapted to target the SCI population in the SCI Exercise Self-Efficacy Scale (ESES), a 10-item questionnaire with each item rated on a 4-point Likert-like scale (Kroll, Kehn, Ho, & Groah, 2007) (Appendix C). Through its development, items were chosen from the Generalized Perceived Self-Efficacy Scale (Jerusalem & Schwarzer, 1992), and McAuley's Exercise Benefits/Barrier Scale (Sechrist, Walker, & Pender, 1987), to create a pool of 50 items that were then reviewed and modified to the current 10 items appropriate to the SCI population (Kroll et al., 2007). In 2012, Kroll et al. tested the hypothesized association between exercise behaviour and exercise self-efficacy in individuals with a SCI. After controlling for demographic variables and clinical characteristics, results from 612 individuals who completed the national (US) survey showed that self-efficacy was the only independent variable that consistently predicted exercise behaviour. Belief in one's own capabilities was significantly related to frequency and intensity of resistance training and aerobic training (Kroll et al., 2012). Curiously, although the literature supports the notion that exercise self-efficacy is an integral part of motivating people with a SCI to get active, recent studies (those published after 2007) that have examined exercise participation and adherence have not specifically tracked exercise self-efficacy as an outcome measure.

1.5 Physical activity peer trainers

Housed in Bandura's theory of efficacy as it relates to behavioural changes, including exercise, is the concept that there are four main sources that influence the development of one's belief in efficacy (Bandura, 1997). These include (1) being successful in one's accomplishment and how this affects the perspective of their ability; (2) the way someone interprets and responds to psychological and physiological states, such as moods, emotions, and stress levels and how these manifest physically can influence the belief you have in yourself; (3) verbal encouragement or constructive feedback often helps to encourage someone or overcome any feelings of doubt; and (4) a vicarious experience by observing someone who is similar to you be successful in a task. In return this can increase the belief in being able to perform the same behaviour and its execution through imitation (Bandura, 1997). Indeed, by focusing on the third and fourth source of influence on self-efficacy, the use of peers has been shown to lead to increased physical activity in SCI through individualized motivation, information sharing, problem solving, observation and feedback (Ginis, Nigg, & Smith, 2013). A peer is someone who shares a common characteristic, culture, or in the case of health behaviours, the same health problem/illness (Webel, Okonsky, Trompeta, & Holzemer, 2010). A peer is also someone who has survived or overcome a shared health experience and is therefore able to provide understanding and advice through experiential knowledge (Ginis et al., 2013).

In a systematic review considering randomized clinical trials assessing the effect of peer-delivered interventions on health behaviours in adults, important changes in physical activity behaviour were found (Webel et al., 2010). Specifically, peer-based interventions have been found to improve access to healthcare services, improve self-efficacy, provide support, and lower health care costs (Doull, O'Connor, Wells, Tugwell, & Welch, 2004). Outcome measures include quality of life, self-efficacy and health-related behaviour change (Doull et al., 2004; Posavac, Kattapong, & Dew, 1999).

The most preferred messengers for the delivery of information/knowledge of PA in SCI has been identified as peers or health care providers (Letts et al., 2011). This has been further supported by the findings from a systematic review that showed interventions delivered by peers versus professionals were equally, if not more, effective when considering physical activity behaviour including exercise frequency, duration and intensity, self-efficacy and exercise motivation, attendance and retention (Ginis et al., 2013). The reason put forth for this was that, in addition to role-modeling, peers were able to provide more tailored or individualized support (Ginis et al., 2013; Letts et al., 2011). Moreover, in practice, health care professionals face multiple barriers such as limited time and staff shortages (Ginis et al., 2013), and so the impact of peers, who have faced a comparable experience, can provide empathetic counsel, role modeling, and enhance health-promoting activities such as physical activity, ultimately providing a greater opportunity for lasting behavioural changes (Webel, Oronosky, Trompeta, and Holzemer, 2010, Ginis et al., 2013).

1.6 Translation of PA guidelines

The current evidence shows that there is still a fundamental gap between the discovery and/or development of healthcare knowledge, in this case PA guidelines for SCI, and the delivery of this knowledge to its end users (Straus, Tetroe, & Graham, 2013). Since the release of the SCI-specific PA guidelines, several studies have been targeted at examining the feasibility and effectiveness of translating this knowledge to different audiences, including community-based organizations, service organizations' websites, support personnel and directly to people with SCI (Gainforth et al., 2013a; Gainforth et al., 2013b; Latimer-Cheung et al., 2013; Ginis et al., 2012; Gainforth et al., 2014; Gainforth et al., 2015). Almost 160 service organizations' websites were inspected to see if they had adopted and integrated the new guidelines into their online services 3, 6, and 9 months after the release of the guidelines. After 9 months, only 51% had done so (Gainforth et al., 2013a). Gainforth et al. (2013) also found that an interpersonal communication through an event-based KT initiative only reached 5% of SCI Ontario clients. Although the guidelines were initially adopted, in general, they were not maintained, as measured only 4 weeks after the event. In a later feasibility study, Gainforth et al., (2015) attempted to translate these guidelines to support personnel using event-based KT initiatives, which involved presentations by an SCI Action Canada researcher, an SCI peer, and SCI Ontario staff member, however similar results were found; although self-efficacy and intent on promoting PA to people with SCI was well adopted during the initiative, it was not maintained even one month later.

In a study employing interviews and focus groups, Letts et al. (2011) explored the perception of people living with an SCI as it relates to preferred messengers and methods for obtaining physical activity information. The results showed that the preferred method was passive media resources such as DVDs, online services or newsletters. The participants emphasized the importance of an interdisciplinary approach, by having different messages from different channels at different times. Similarly, when looking at overall health, a study by Galea, Tumminia, & Garback, (2006) also found that by using a more comprehensive multifaceted approach through the use of the telephone, messaging devices and videos, they were able to effectively monitor newly discharged patients and deliver care for several comorbidities including diabetes, obesity, bladder infections, wounds and depression. The success from the telemedicine and E-health approach by Galea et al. (2006) was purportedly based on the customized and individualized approach. This common thread of individualization appears in most literature when discussing behavioural changes and self-regulation as it relates to physical activity and health in SCI (Boschen, Tonack, & Gargaro, 2003; Galea et al., 2006; Letts et al., 2011).

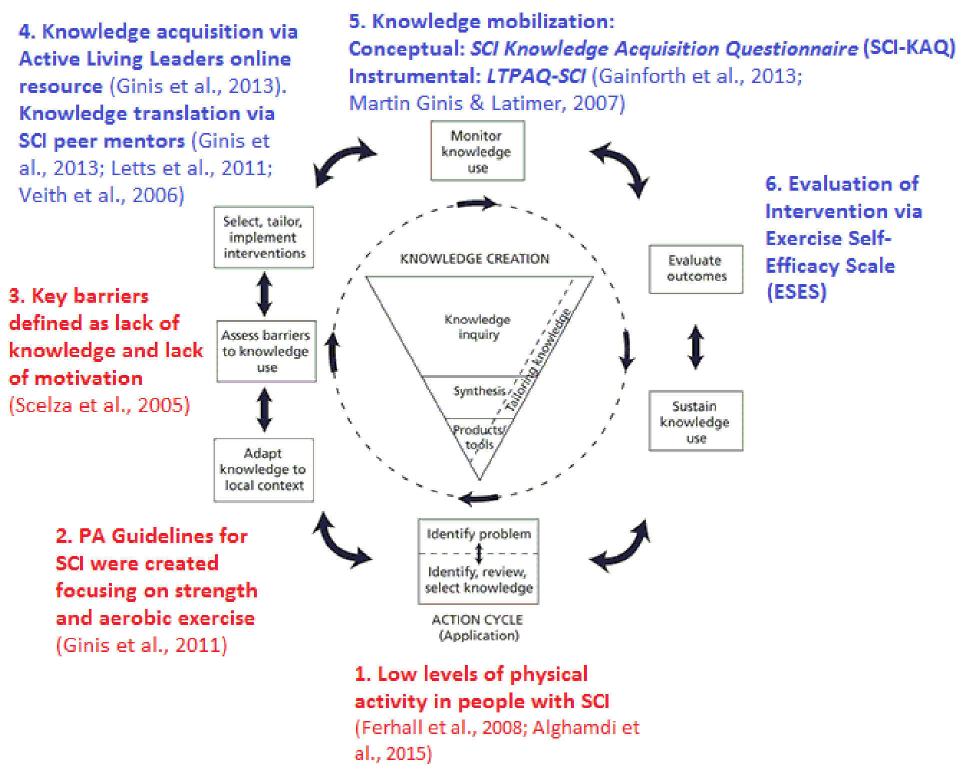
Based on these findings about the preferred methods for delivering PA information to people with a SCI, McMaster University and Action Canada released an online resource for translating the physical activity guidelines for SCI, ‘Active Living Leaders’ (October, 2014). However, although utilizing an online service is reported as a preferred method (Letts et al., 2011), this strategy can also have some limitations in that the information is not individualized or interactive (Ginis et al., 2010). Moreover, although online services may translate the knowledge, the knowledge may not be put into action (knowledge mobilization). To address this gap, further research is required, perhaps using a combined strategy to pair online services with an individualized approach to achieve the desired outcome of increasing PA levels in people living with a SCI.

Chapter 2: Summary and rationale

Evidence indicates that engaging in exercise has the potential to improve and/or maintain functional ability, aerobic fitness, strength, pain, quality of life, and decrease the risk of chronic disease and depression for those with a SCI (Latimer-Cheung et al., 2013). Since the release of the SCI specific PA guidelines, it has been suggested that this information has neither been effectively translated to, nor mobilized by its target population (Ginis et al., 2011; Alghamdi et al., 2015). Increasing exercise self-efficacy is key to overcoming the intrinsic barriers that address lack of motivation and changes in exercise behaviour, however as aforementioned, informational barriers such as lack of knowledge or information are also attributed to low levels of participation (Rimmer et al., 2004). To this point, the knowledge now exists with the SCI specific PA guidelines and yet lack of knowledge is still reported as one of the main barriers (Ginis et al., 2011). The translation of these guidelines to its target population is clearly a barrier that still needs to be addressed. Driven by Bandura's theory of efficacy, an important influence in developing the belief and therefore success in being able to perform a behaviour (i.e. physical activity), is by vicarious experience of a similar other, such as can occur through peer modelling (Bandura, 1997). Indeed, the use of peers has been shown to lead to increased physical activity in SCI through motivation, information sharing, problem solving, observation and feedback (Ginis et al., 2013). Moreover, support from someone who has endured the same experience can increase quality of life and decrease rates of secondary health problems (Veith et al., 2006); Blosser & De Pompei, 1995).

Knowledge acquisition is a method of learning required for a knowledge-based system, and the first step is the uptake of the knowledge that needs to be translated. Knowledge translation has been defined as "the methods for closing the gaps from knowledge [acquisition] to practice" and has been formally defined by Canadian Institutes of Health Research (Straus, Tetroe, & Graham, 2009). The use of knowledge can fit into several classifications, but for our purposes, we will refer to its conceptual use, in that we aim to make "changes in knowledge, understanding and attitudes" and its instrumental use in an effort to effect "changes in behaviour or practice" (Straus, Tetroe, & Graham, 2010). The work proposed in this thesis is situated within this knowledge-to-action framework and the specific issues pertaining to the SCI population are outlined in Figure 1. This framework outlines (1) the identified problem, (2) the creation and synthesis of the knowledge and how it has been customized and adapted, and (3) the assessed barriers that have been identified from previous studies. Previous studies support the selection of our intervention (4), which will combine online media to acquire the knowledge of these guidelines and the translation of this knowledge through peer trainers. In this thesis, the effectiveness of translating and mobilizing this knowledge into active use will be assessed (5), and changes in exercise self-efficacy will be measured as the primary outcome of our selected intervention (6).

Figure 2.1 – Knowledge-to-action framework with study specific considerations outlined in red and blue (Graham, Logan, Harrison et al., 2006).



2.1 Study purpose

The overall objective of this study is to compare the effectiveness of SCI peer trainers versus student trainers (control) on the translation of physical activity guidelines, their impact on intrinsic barriers to exercise and exercise self-efficacy, and the level of physical activity participation in people with SCI.

2.2 Specific aims

1. To compare the translation of knowledge about physical activity guidelines in people with SCI who receive it from a peer versus student trainer.
2. To describe the changes in the reported barriers to exercise in people with SCI following a 3-month peer trainer program vs. a 3-month student trainer program.
3. To compare the immediate effects on exercise self-efficacy in people with SCI following an initial meeting with a peer trainer vs. student trainer.
4. To evaluate the changes in exercise self-efficacy in people with SCI over a 3-month peer trainer program vs. a 3-month student trainer program.
5. To evaluate the changes in physical activity participation levels in people with SCI over a 3-month peer trainer program vs. a 3-month student trainer program.

2.3 Hypotheses

1. Knowledge translation about SCI physical activity guidelines will be equally effective whether the knowledge is delivered via a peer or student trainer to people with SCI.

2. Peer trainers will be more effective than student trainers in addressing the intrinsic barriers of exercise in people with SCI over time with a 3-month peer trainer program vs. a 3-month student trainer program

3. Peer trainers will have a larger immediate effect on exercise self-efficacy compared to student trainers.

4. Peer trainers will be more effective than student trainers in improving exercise self-efficacy in people with SCI over time with a 3-month peer trainer program vs. a 3-month student trainer program.
5. People with SCI who meet with a peer trainer will have higher levels of physical activity participation levels over time with a 3-month peer trainer program versus a student trainer program.

2.4 Methods

Design: Randomized controlled trial.

2.4.1 Trainers and participants

Peers and Student trainers: Four peer trainers with a traumatic spinal cord injury volunteered to be the peer trainers (1 male and 1 female with paraplegia, and 1 male and 1 female with tetraplegia), each were PARC participants >1 year enrollment. Four 3rd or 4th year kinesiology student trainers (2 males, 2 females) also volunteered to participate in the study. All peer trainers were PARC members and all students were PARC volunteers. They were all meeting the recommended PA guidelines for SCI or able-bodied (>40 min/week and >150 min/week, respectively) and willing to volunteer 2-6 hours/week for a minimum of 3 months. The specific characteristics of the peer and student trainers are summarized in Table 2.1.

Table 2.1 Peer and student trainer characteristics

Peer trainers	Sex	Age (yrs)	Injury level	Degree of Paralysis	Weekly moderate PA (mins)
Peer 1	M	34	T4	complete	180
Peer 2	F	48	T5	complete	125
Peer 3	M	43	C7	incomplete	120
Peer 4	F	24	C5/6	incomplete	240
Student trainers	**Sex**	**Age (yrs)**	**Time at PARC**	**Year of Degree**	**Weekly moderate PA (mins)**
Student 1	M	33	2 yrs	3rd	180
Student 2	F	23	1.5 yrs	3rd	90
Student 3	M	23	2.5 yrs	3rd	270
Student 4	F	23	2 yrs	4th	240

SCI Participants: Our recruitment criteria included adult (18-65 years old) traumatic SCI participants (> 6 months post SCI) who were a current or interested participant at PARC, and who were not currently meeting the recommended weekly PA guidelines (<40 min/week). A completed PARmed-x form and reliable transportation to and from the PARC were required. Exclusion criteria included any cardiovascular condition, musculoskeletal injuries, or any other health or medical condition for which exercise is contra-indicated, or a history of stroke, or other chronic condition due to brain injury.

2.4.2 Research setting

The Physical Activity Research Centre (PARC) is an accessible, state-of-the-art exercise facility for the local SCI community offering a 12-station HUR strength training equipment suite specially designed for people with disabilities; 2 GameCycles™, which are video game-based arm ergometers, 2 SCI Fits, a NuStep and a Theratrainer, which offer passive leg movement during aerobic arm cycling, and an EasyStand Glider.

2.4.3 Procedures

Peer and student trainers completed the online Active Living Leadership course (http://activelivingleaders.ca/) within 2 weeks of enrollment. The KT coordinator conducted an individual meeting with each peer/student trainer the following week after completion of the training program to discuss any questions or concerns. This meeting also provided an opportunity to confirm that the peer and student trainers had successfully acquired the knowledge provided by the online training program. Specific topics for translation included: the physical activity guidelines for SCI, resources for information on sport participation and other ways of staying active in their community, common barriers that people with SCI face when trying to access physical activity, strategies to overcome these barriers, and some basic principles to motivate, set goals and take an individualistic approach to become an effective peer trainer. These topics were directly based on the material derived from the online Active Living Leaders resource.

SCI participants met with the KT coordinator individually to obtain consent and complete an intake form (Appendix A). This form gathered participant characteristics including age, gender, injury level, years since injury, current living arrangements, method of transportation, and income. This form also inquired about the participants' current level of physical activity or exercise as well as had them to list their top 3 barriers that prevent them from exercising. Participants were also asked if they had heard of the SCI Action Canada guidelines for exercise and if so, to list them, to assess their baseline knowledge.

SCI participants were then randomly assigned (using Excel's RAND function to generate random number assignment) to either a peer or student trainer and pairs were matched based on gender. Those who were assigned to an SCI peer trainer were also matched according to injury classification (paraplegia or tetraplegia). Initial contact between the participants and their peer/student trainer started with either a phone call or email to decide on a mutually convenient time for the first meeting. The first meeting, along with all further data collection took place at the Blusson Spinal Cord Centre (818 W. 10th Ave), online or via telephone/text. The participants and peer/student trainers were expected to meet in person only once for the translation of the knowledge, goal setting and design of an individualized workout regimen and then it was up to the pair if they would like to continue meeting. The initial interaction between the peer or student trainer and the participant was audio recorded and later audited by a PhD student at the University of Toronto. The auditor completed a form (Appendix B) to confirm that the appropriate topics were discussed and that the information was delivered and expressed correctly.

After this initial meeting, it was up to the participant to determine when and how they met with their peer/student trainer. Using a log sheet (Appendix C), peer and student trainers tracked the number of times and topics discussed with each participant post initial intervention.

2.4.4 Outcome measures

Knowledge Translation Effectiveness of knowledge translation (via online knowledge acquisition) was measured in the participants using a multiple-choice questionnaire, with questions based on the modules used in the Active Living Leadership online course. Only those questions that directly tested knowledge of the SCI Physical Activity Guidelines and sport participation were selected to create the Spinal Cord Injury Knowledge Acquisition Questionnaire (SCI-KAQ). (Appendix D).

Barriers Barriers were categorized into extrinsic and intrinsic barriers and then further subdivided into a) Extrinsic Barriers: i) resource availability, ii) cost/economic, and iii) lack of equipment, and b) Intrinsic Barriers: i) knowledge, education, and training, ii) emotional/psychological, and iii) secondary health concerns. Upon intake, participants listed their top 3 self-reported barriers to exercise. During the exit interview, participants were asked to rate the degree (1 – not at all and 10 – fully) to which their original listed barriers were addressed, and to identify their current top 3 self-reported barriers to exercise they are facing since the intervention (Appendix E). The extent to which barriers were addressed was measured by using a scale from 1-10 with 1 being not addressed at all and 10 being fully addressed.

Exercise Self-Efficacy Exercise self-efficacy was measured by the SCI Exercise Self-Efficacy Scale (SCI-ESES) adapted from Kroll et al. (2007) (Appendix F), a self-reported measure consisting of 10 items, each rated on a scale from 1 (*not at all true*) to 4 (*exactly true*). The SCI-ESES score is calculated by the sum of 10 items, and total score can range from 10-40. A higher score indicates more exercise self-efficacy. This measure has been reported to have good internal consistency (Cronbach's $\alpha = 0.87 – 0.93$) and test-retest reliability (Equal-Length Spearman-

Brown test = 0.8836) (Kroll et al., 2007). We also confirmed internal consistency in our setting (Cronbach's $\alpha = 0.90$).

Physical Activity Participation Changes in physical activity participation levels were assessed using the LTPAQ-SCI (Appendix G) questionnaire. This measure was chosen as it has shown good validity and test-retest reliability (Ginis et al., 2012). This measure asked the participant about the amount of time that they spent engaging in mild, moderate and heavy intensity leisure time physical activity over the last 7 days and how many minutes spent doing PA per day. This measure allowed us to investigate physical activity levels in multiple (3 different) ways. As the PA guidelines for SCI suggest that PA should be performed at a moderate intensity, we focused our results on this, however we also considered the total amount of PA over a week and whether the participants were meeting the recommended guidelines or not at each time point.

Knowledge acquisition in the SCI participants was confirmed after their initial meeting with their peer or student trainer. The ESES and LTPAQ-SCI were measured at baseline (intake), and then 1, 4, and 12 weeks after the initial meeting.

An exit survey was also administered to each participant by the KT Coordinator 6 months after intake. Participants were asked to rate their overall satisfaction in 7 areas of the study and/or any changes they would like made to the study design. Lastly, they responded to an open ended question about their experience and how they think it may have differed should they have been randomized to the other group (Appendix E). The timeline of administration of each of the outcome measures is outlined in Figure 2.2.

Figure 2.2 – Procedural timeline for peer/student trainers and participants

Week #:	-3	-2	-1	1	2-4	4-12	24
PEER/STUDENT TRAINERS' ACTIVITIES	Online Active Living Leaders Course		Meet with KT Coordinator	Meet with Peer/ Student trainer	Peer/ Student trainer - Participant meetings as requested		
PARTICIPANTS' ACTIVITIES				Meet with Peer/ Student trainer	Peer/ Student trainer - Participant meetings as requested		

Baseline
- LTPAQ-SCI
- ESES
- Barriers

Week 1
- SCI-KAQ
- LTPAQ-SCI
- ESES

Week 4
- LTPAQ-SCI
- ESES

Week 12
- LTPAQ -SCI
- ESES

6-month follow-up
- Exit interview
- Barriers

2.5 Statistical analysis

All statistical analyses were conducted using SPSS (IBM Corp, Armonk, NY) and statistical tests were evaluated at an alpha of 0.05. Most data followed a normal distribution. Normality of the data was assessed using the Shapiro-Wilk test as well as visual inspection of raw data plots. Data that were skewed, was normalized using the transformation log function in SPSS. We also analyzed some of our data using non-parametric statistics.

The following analyses were conducted to test each of the hypotheses (re-stated for convenience):

Hypothesis 1: Knowledge acquisition about SCI physical activity guidelines will be equally effective whether the knowledge is delivered via peer trainers or student trainers to people with SCI.

Effectiveness of knowledge translation was measured by the SCI-KAQ scores after meeting with the peer vs. student trainer group and supported by an audio recorded audit. A Mann-Whitney U-test was used to determine any significant difference in SCI-KAQ scores between the peer and student trainer group.

Hypothesis 2: Peer trainers will be more effective than student trainers in addressing the intrinsic barriers of exercise in people with SCI over time with a 3-month peer trainer program vs. a 3-month student trainer program

The degree in which the self-reported intrinsic barriers to exercise was measured by using a scale of 1 (not at all) to 10 (completely). A Mann-Whitney U-test was used to determine any significant difference in the rated scores between the peer and the student trainer group.

Hypothesis 3: Peer trainers will have a larger immediate effect on exercise self-efficacy than student trainers.

The change in ESES scores from baseline to week 1 was compared between peer and student trainer pairs with SCI using a t-test.

Hypothesis 4: Peer trainers will be more effective than student trainers in improving exercise self-efficacy in people with SCI over time with a 3-month peer trainer program vs. a 3-month student trainer program.

A 2 (peer, student trainer) × 2 (baseline, week 12) repeated measures ANOVA was used to compare the changes in the ESES scores between the two groups over the time period of the study. No post-hoc analyses were warranted.

Hypothesis 5: People with SCI who meet with a peer trainer will have higher levels of physical activity participation levels over time with a 3-month peer trainer program versus a student trainer program.

A 2 (peer, student trainer) × 2 (baseline, week 12) repeated measures ANOVA was used to compare the changes in the LTPAQ-SCI scores between the two groups over the time period of the study. No post-hoc analyses were warranted.

Chapter 3: Results

3.1 Participant characteristics

Ten participants with a traumatic spinal cord injury (7 males, 3 females) volunteered to participate in this study. Two of the ten participants did not complete the study due to secondary health conditions. The average age of the participants was 43.3 (range: 24-65 years) and 7 were paraplegic, 3 tetraplegic. All participants were members of the Physical Activity Research Centre (PARC), however none were achieving the recommended PA guidelines for SCI. Participant characteristics are summarized in Table 3.1.

Table 3.1 Participant characteristics

Subject	Sex	Age (yrs)	Injury level	Degree of Paralysis	Years post-injury	Living arrangements	Method of transportation	Income/ support	Peer/ Student trainer
P1	M	52	T3/4	complete	33	Spouse	Own vehicle	Disability	Peer 1
P2	M	24	L3	incomplete	1	Family	Public	Insurance	Peer 1
P3	M	45	T11	complete	3	Single	Own vehicle	Employed	Peer 1
P4	M	32	T5	incomplete	1	Spouse	Public	Disability	Peer 1
P5	M	53	C3/4	Incomplete	28	Family	Public	Disability	Peer 3
S1	M	32	C5/6	incomplete	5	Family	Public	Insurance	Student 3
S2	M	45	C4/5	incomplete	30	Single	Power chair	Disability	Student 3
S3	F	50	L5-S1	incomplete	11	Single	Own vehicle	Employed	Student 4
S4	F	35	T5/6	complete	24	Family	Parents	Employed	Student 4
S5	F	65	T12	incomplete	1	Single	Public	Disability	Student 2

P – Assigned to SCI peer trainer
S – Assigned to Student trainer

3.2 Knowledge translation

Of the 10 participants, only 2 responded that they had heard of the SCI Action Canada Guidelines at baseline however none were able to identify the specific guidelines correctly. After completing the SCIKAQ, the median score for the translation of knowledge from participants paired with a SCI peer trainer was 13.5 (range: 13-14) and the median score from participants paired with a student trainer was 14 (range: 10-15) (Fig. 3.1). A Mann-Whitney U-test indicated that there was no significant difference in SCIKAQ scores between the peer and student trainer group (U=8.0, p =.592).

Figure 3.1 Results from the translation of knowledge from peer trainers and student trainers to participants after the first interaction.

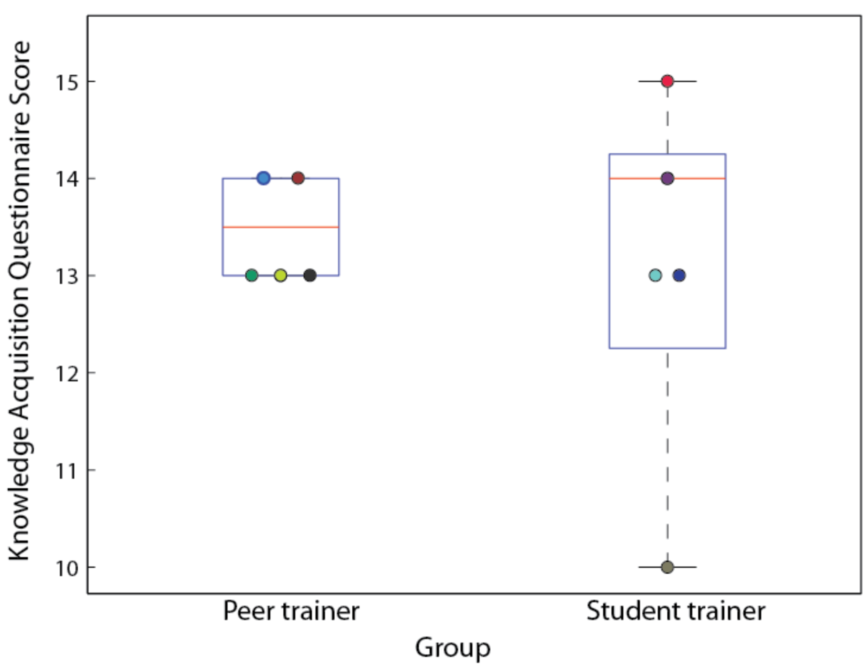


Figure 3.1 depicts the scores of the knowledge acquisition questionnaire for both the peer and student trainer groups. The distribution is expressed within the boxes, with the orange line depicting the median for each group. The dotted lines show the range and the individual coloured circles showing each participant.

The review of audio recordings from the initial meeting between participants and their peer or student trainer confirmed that all SCI exercise guidelines were delivered with 100% accuracy across groups during the initial meeting (all items in Appendix B were checked off by the independent auditor). Figure 3.2 provides a schematic illustrating the nature and prevalence of the topics discussed across participants in each group.

Figure 3.2 A & B Word diagrams of topics discussed during initial meeting between participants and SCI peer trainers and Student trainers.

A. SCI Peer trainer group

B. Student trainer group

Figure 3.2 A & B depict the topics discussed between participants and the SCI peer trainers or student trainers. The sizing of the words is scaled to the frequency of occurrence of the word discussed during the initial meeting.

The peer trainer group seemed to discuss more personal topics, such as relationships and finances, as well as specifics relating to living with a SCI such as autonomic dysreflexia and wheelchair use over and beyond the required exercise information. The student group addressed more items relating to the exercise (kinesiology) field such as physiology, exercise alternatives and stretching. The student trainer group also discussed in greater detail topics related to exercise physiology and the human body whereas the peer trainer group focused more on specific modifications for injury type and common side effects of exercise and SCI. A common topic in all meetings included community and social support.

The average number of meetings between the peer trainers and their participants ranged from 2-6 meetings with an average of 3.3 over the course of 3 months. The average number of meetings between the student trainers and their participants was 4.8 with a range of 0-11 meetings. Meetings between participants and peer trainers ranged from 5-30 minutes with an average of 19 minutes per meeting whereas the time spent between participants and their student trainers ranged from 20-150 minutes with an average of 70 minutes per meeting.

Figure 3.3 Logged meetings between participants and their peer/student trainer

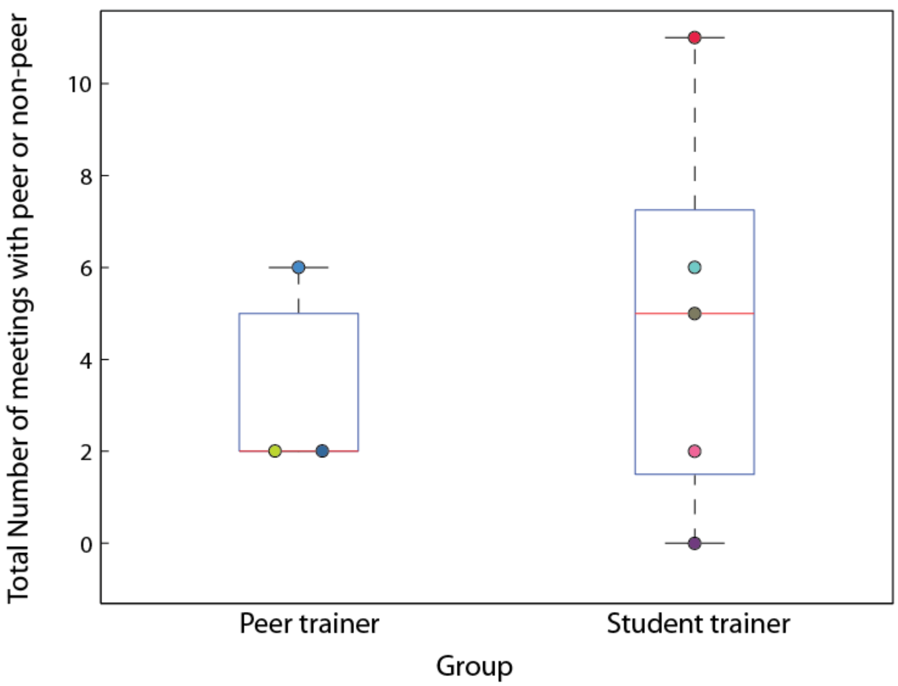


Figure 3.3 represents the degree to total number of meetings participants had with both the peer/student trainer groups. The distribution is expressed within the boxes, with the orange line depicting the median for each group. The dotted lines show the range and the individual coloured circles showing each participant.

General topics that were discussed during these logged meetings are shown in a frequency graph in figure 3.4.

Figure 3.4 Frequency graph of topics discussed during each meeting between participants and SCI peer or student trainers.

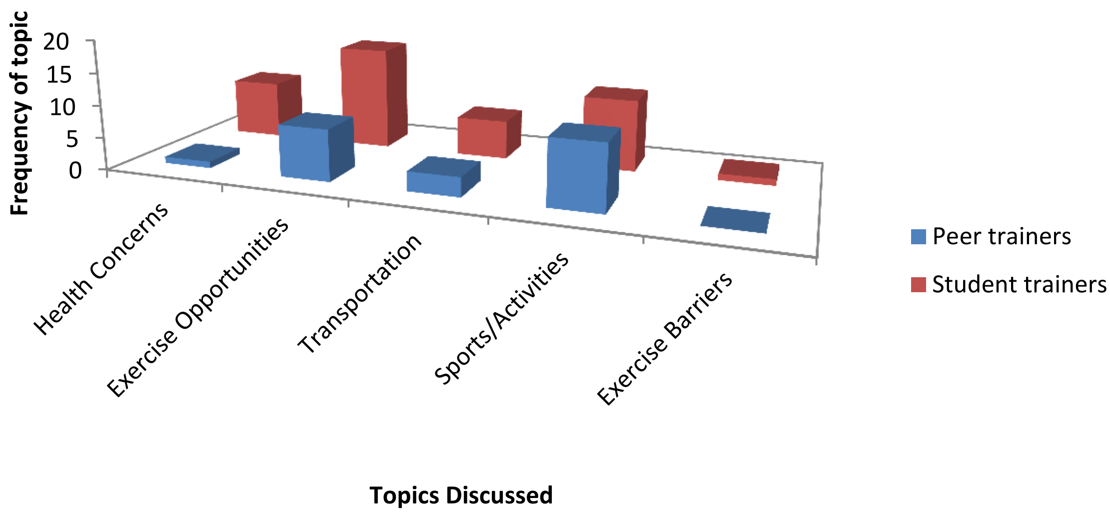


Figure 3.4 shows the number of times a common topic was discussed during logged meetings between participants and peer and student trainers.

When considering other topics that were discussed during these meetings, only other resources offered at the ICORD centre and wheelchair maintenance came up between participants and their peer trainers. This could be due to the fact that most participants in the peer trainer group were all assigned to the same trainer due to the prevalence of male, paraplegic participants in this group. The other specific topics logged between participants and peer or student trainers are displayed in Figure 3.5.

Figure 3.5 Word diagram of topics discussed during logged meetings between participants and peer or student trainers.

Figure 3.5 depicts the topics discussed between participants and peer or student trainers. The sizing of the words is scaled to the frequency of occurrence of the word discussed during the logged meetings.

3.3 Barriers

Table 3.2 lists the top 3 barriers self-reported at intake. Most notable is the fact that almost all barriers listed were intrinsic (depicted with red text). Although participants were randomly assigned to either the peer or student trainer group, we observed that participants assigned to the student group tended to list lack of energy and/or pain as their top 3 barriers whereas none of these factors were identified by participants in the peer trainer group, suggesting a possible confounding variable.

Table 3.2 Top 3 self-reported barriers to participating in PA

Subject	Time	Barrier 1	Barrier 2	Barrier 3
P1	Intake	Do not know where to exercise†	Lack of accessible equipment¥	Health conditions prevent exercising∞
	Exit	Lack of time§	Lack of energy§	Lack of motivation§
P2	Intake	Lack of time §	Lack of motivation§	Lack of accessible equipment¥
	Exit	Lack of time§	Lack of transportation‡	Lack of accessible equipment¥
P3	Intake	Lack of time§	Lack of accessible equipment¥	Exercise will not help my condition§
	Exit*			
P4	Intake	Lack of transportation‡	Lack of accessible equipment¥	Do not know where to exercise†
	Exit	Lack of time§	Lack of transportation‡	Lack of accessible equipment¥
P5	Intake	Do not know where to exercise†	Lack of accessible equipment¥	Health conditions prevent exercising∞
	Exit*			
[redacted]				
S1	Intake	Lack of energy§	Lack of education/ training†	Lack of motivation§
	Exit	Lack of energy§	Lack of motivation§	Health conditions prevent exercising∞
S2	Intake	Lack of energy§	Health conditions prevent exercising∞	Pain§
	Exit	Lack of motivation§	Pain§	Weather‡
S3	Intake	Lack of energy§	Lack of education/ training†	Health conditions prevent exercising∞
	Exit	Health conditions prevent exercising (fear)∞	Pain§	Distance (too far from home)‡
S4	Intake	Lack of time§	Lack of energy§	Pain§
	Exit	Lack of time§	Lack of energy§	Pain§
S5	Intake	Lack of energy§	Lack of education/ training†	Pain§
	Exit	Lack of energy§	Lack of transportation‡	Pain§

Table 3.2 Top 3 self-reported barriers to participating in PA

Extrinsic barriers depicted in blue, intrinsic barriers depicted in red
*withdrew from study
‡ Resource Availability
¥ Equipment
†Knowledge, education, and training
§Emotional/Psychological
∞Secondary health concerns

Figure 3.6 Categories of top 3 self-reported barriers at time of intake (A) and at 6-months follow-up (B)

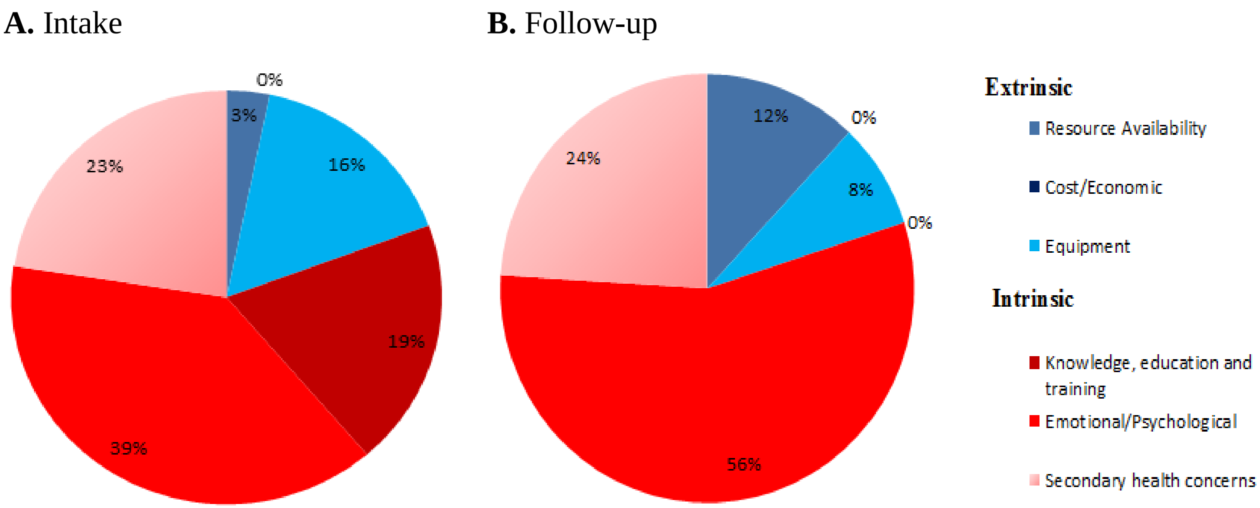


Figure 3.6 A & B the top 3 self-reported barriers before and after the intervention for all participants. Barriers are separated into extrinsic and intrinsic.

Inspection of the changes in the top 3 self-reported barriers from intake to the exit interview at 6 months reflect that lack of education/training are no longer in the top 3, whereas resource availability and emotional/psychological barriers were more prominent by the end of the study.

At the exit interview, the median score of the peer trainer group when asked to rate the extent to which they perceived their barriers were addressed was 6.5 (range: 6-7). For the student trainer group, the median score was 6.2 (range: 4-8). A Mann-Whitney U-test showed there was no significant difference in these scores between the peer and student trainer groups ($U=7.0$, $p=.878$).

Figure 3.7 Degree to which barriers to exercise have been addressed since the intervention

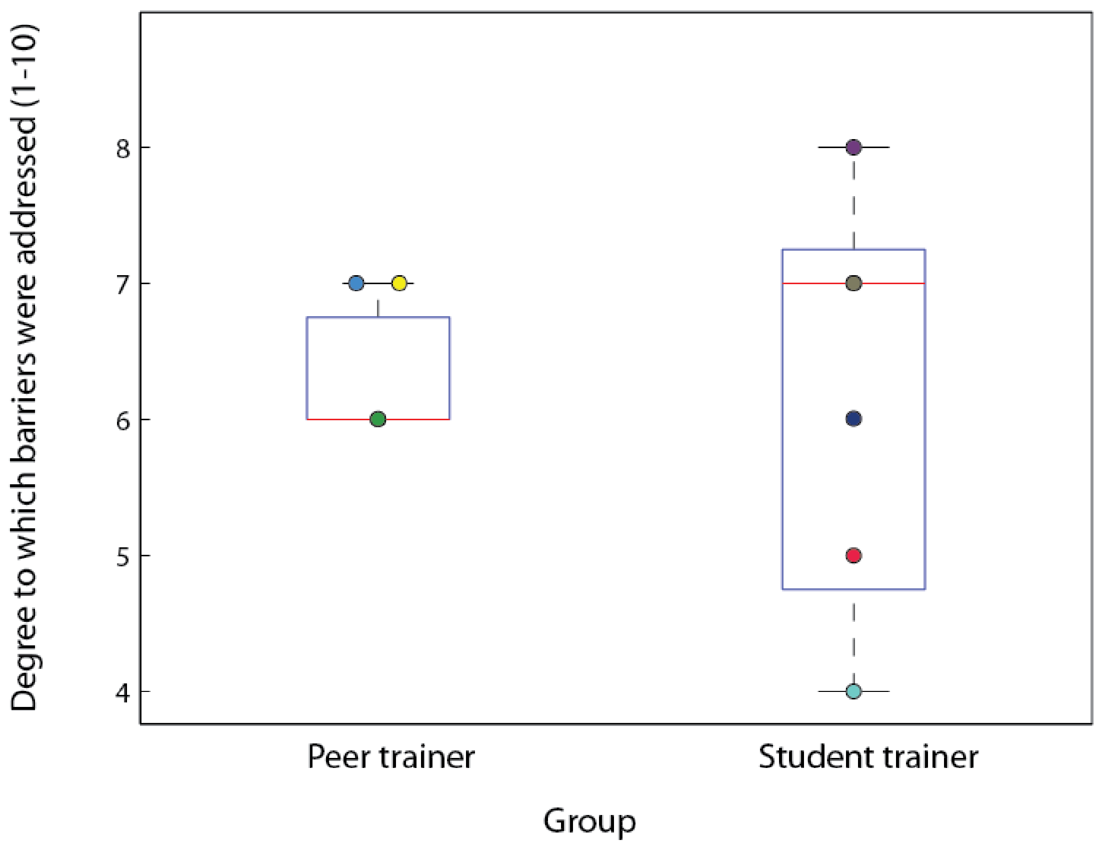


Figure 3.7 represents the degree to which barriers were addressed for both the peer and student trainer groups. The distribution is expressed within the boxes, with the orange line depicting the median for each group. The dotted lines show the range and the individual coloured circles showing each participant.

3.4 Exercise self-efficacy

We anticipated an immediate change in exercise self-efficacy following the initial meeting between peer/student trainer and participant pairs. However, there was no significant difference between the ESES change scores in the peer trainer group (M= -4.25, SD=2.29) and those from the student trainer group (M= -0.20, SD=1.82) between intake and week 1 (t (7) = 1.32, p=.203).

Figure 3.5 plots the raw ESES scores recorded over the course of the 3 months in each group. Interestingly, both groups showed a pattern of reduced ESES score after the initial visit with their peer or student trainer. However, a 2x2 repeated measures ANOVA comparing intake vs. week 12 ESES scores between peer and student trainer groups showed no main effect of group ($F(1,8) = 2.16$, $p = .192$) or time ($F(1,8) = .779$, $p = .411$). These results suggest that meeting with either a peer or student trainer did not have an effect on exercise self-efficacy and there was no overall effect on exercise self-efficacy over time.

Figure 3.8 Exercise Self-Efficacy Scores between groups at baseline, week 1, 4, and 12

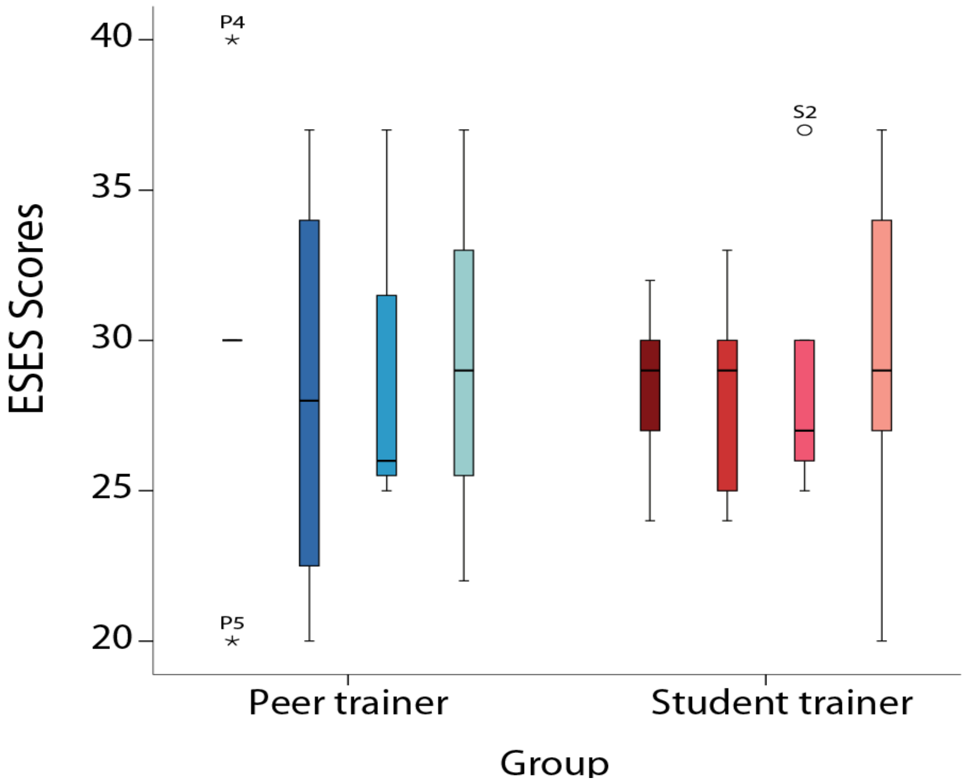


Figure 3.8 represents the exercise self-efficacy scores at four time points for both the peer and student trainer groups. The distribution is expressed within the coloured bars with the black line within depicting the median. The vertical black lines show the range for each group at each time point. An asterisk and a circle represent outliers within a group.

3.5 Physical activity levels

Through the use of the Leisure Time Physical Activity Questionnaire for SCI (LTPAQ-SCI) we determined whether participants were meeting the recommended physical activity guidelines for SCI at each of the four time points over the 3 months of the study. Not surprisingly, none of the participants were meeting the guidelines at time of intake. However, by week 1, 75% of the participants from the peer trainer group and 80% of participants from the student trainer group met the guidelines after their initial meeting. By week 12, all of the participants from the peer trainer group and all but 1 from the student trainer group were meeting the recommended guidelines (Fig. 3.9).

Figure 3.9 Total # of participants meeting the Guidelines at baseline, week 1, 4, and 12.

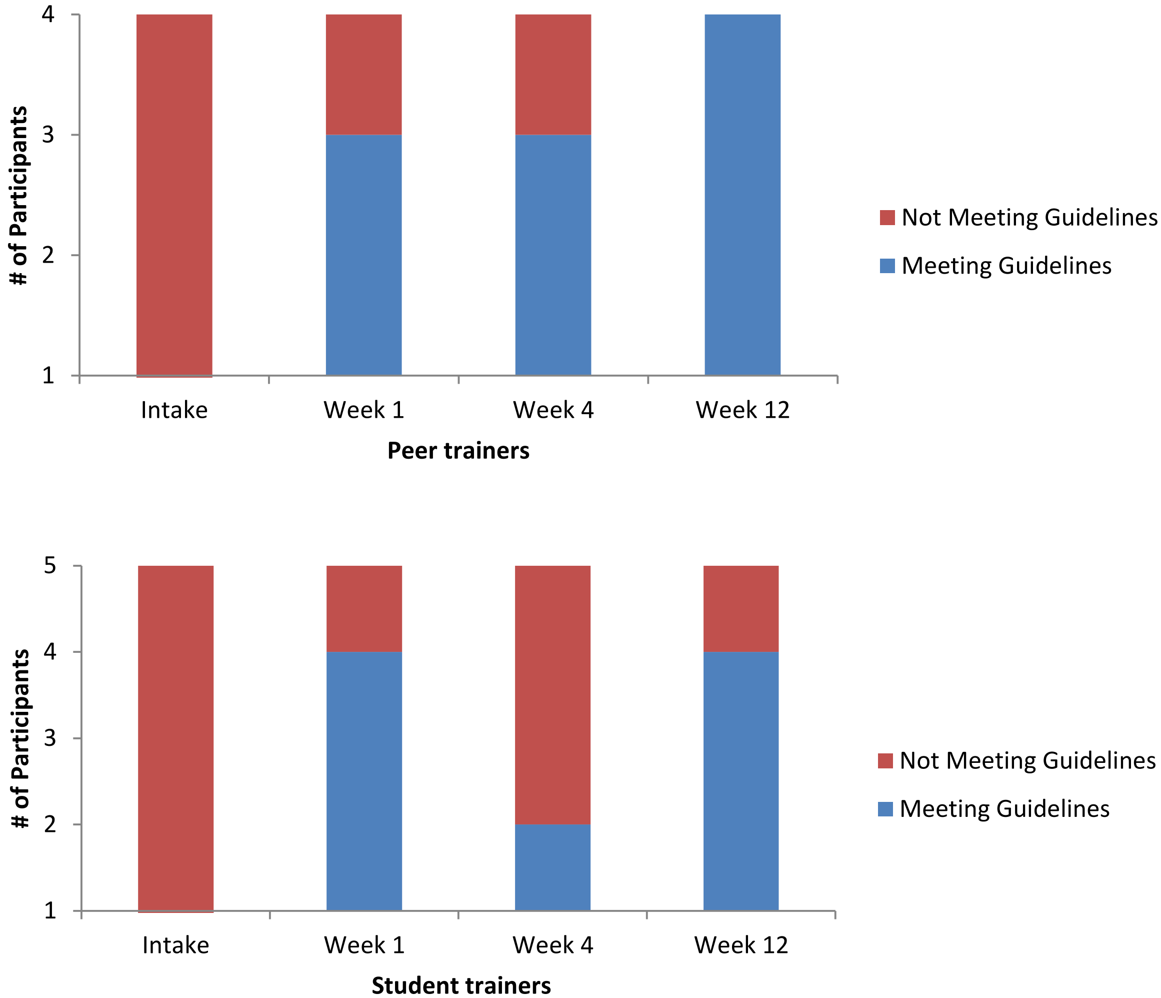


Figure 3.9 shows the total number of participants who were meeting the guidelines at intake, week 1, week 4, and week 12 in the peer and student trainer groups.

Figure 3.10 Total number of minutes/week of moderate leisure time activity

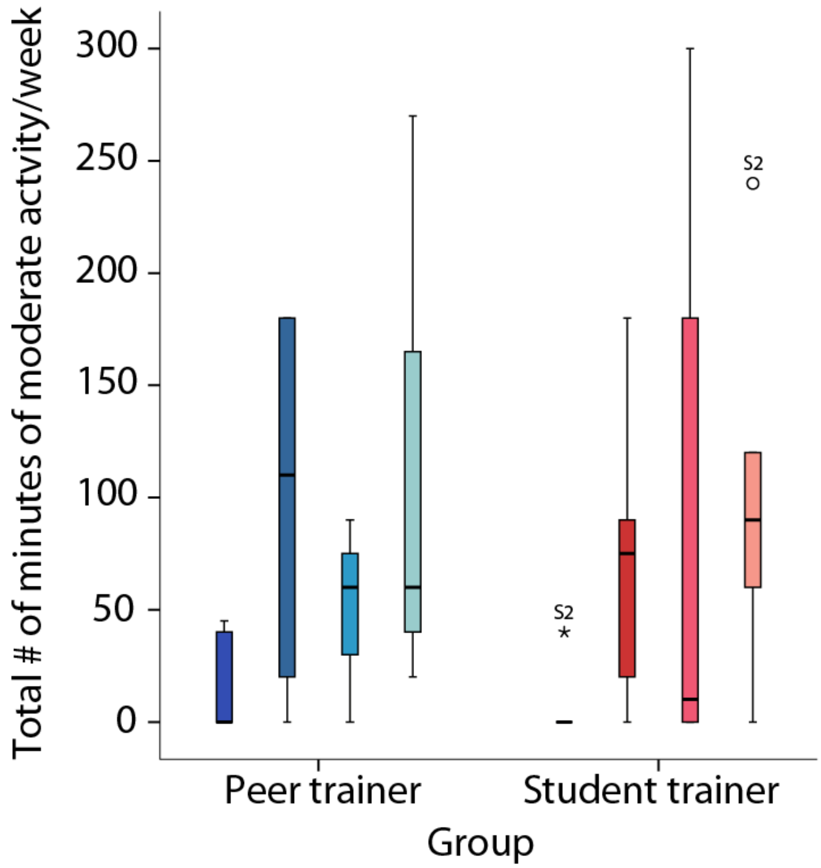


Figure 3.10 demonstrates the total number of minutes of moderate intensity activity per week at four time points for both the peer and student trainer groups. The distribution is expressed within the coloured bars with the black line within depicting the median. The vertical black lines show the range for each group at each time point. An asterisk and a circle represent outliers within a group.

Accordingly, the total number of minutes per week of moderate activity between groups also appeared to increase over the duration of the study. Although there was no difference in the amount of time dedicated to moderate physical activity between the groups (F(1,8) = .001, *p = .979*) there was a significant overall increase in the amount of time dedicated to moderate physical activity time across both groups (F(1,8) =7.64 *p = .033*). Similarly, analysis of the total number of minutes/week dedicated to PA (including mild, moderate and heavy intensity) indicated that the increase in PA between intake and week 12 approached significance (F(1,8) = 5.904, *p* = *.051*), but no main effect of group (F(1,8) = 1.107, *p* = *.333*).

Figure 3.11 Total number of minutes/week of all leisure time activity

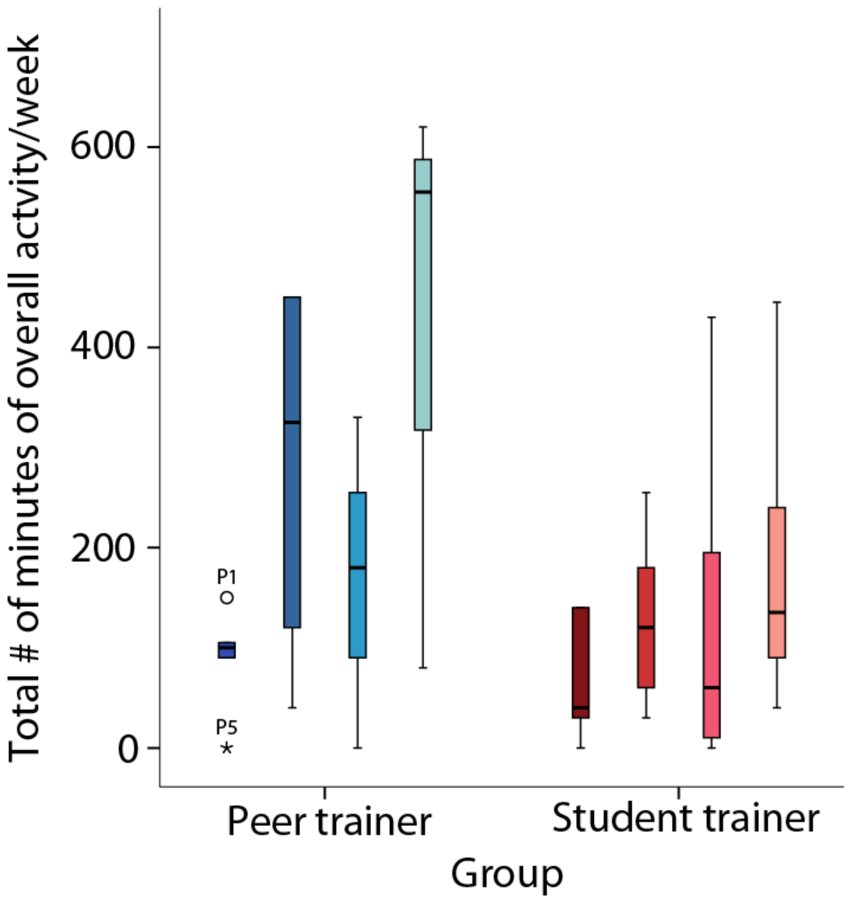


Figure 3.11 demonstrates the total number of minutes of mild, moderate, and heavy intensity activity per week at four time points for both the peer and student trainer groups. The distribution is expressed within the coloured bars with the black line within depicting the median. The vertical black lines show the range for each group at each time point. An asterisk and a circle represent outliers within a group.

3.6 Satisfaction questionnaire and exit interview

Overall, participants rated their experience with their peer or student trainer positively and would participate in a similar study again. They also perceived an improvement in their aerobic activity and strength training overall (consistent with our measure of total amount of weekly physical activity). Positive ratings were also found with their comfort in interacting with their peer or student trainer and their perceived effectiveness and ratings showed a strong likelihood that participants would recommend this study to others.

Figure 3.12 Results from exit survey between peers and student trainers

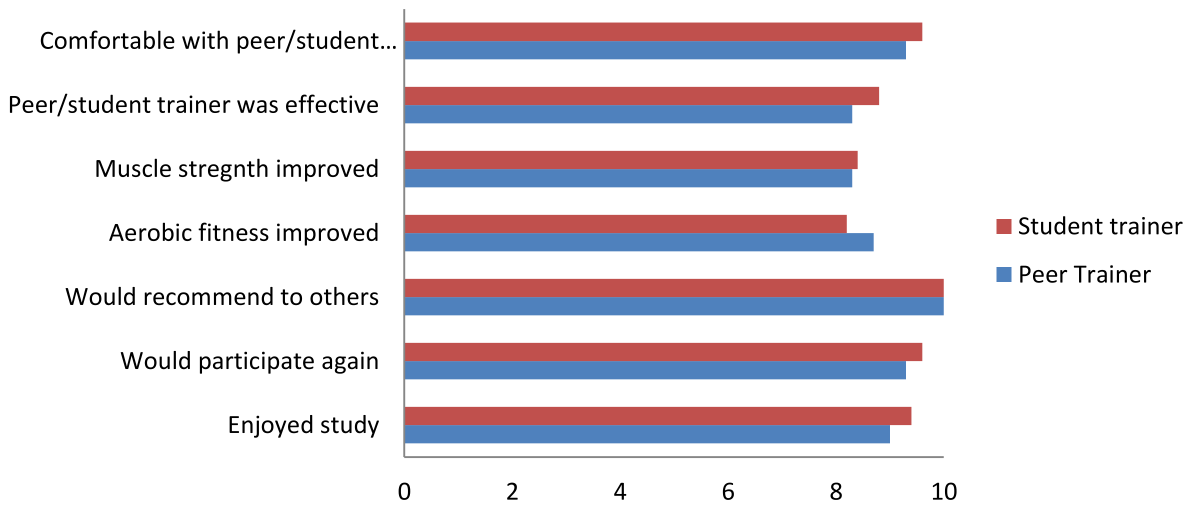


Figure 3.12 shows the average score from 1-10 (1 being disagree and 10 being agree) of the satisfaction questionnaire for both the peer and student trainer groups.

When considering the open-ended question relating to possibility of being randomly assigned to the other group, participants were split on whether they would have preferred a student or a peer trainer. Some reported appreciating speaking with someone with the same experience whereas others reported that they preferred student trainers, as they were perceived to be more knowledgeable in regards to fitness or setting exercise goals, or that they felt they would benefit more from a specialized trainer than peer support.

Chapter 4: Discussion

In this pilot study, we sought to compare the effectiveness of student trainers vs. SCI peer trainers on knowledge translation and mobilization surrounding physical activity in people with SCI. We considered the impact that peer and student trainers would have on perceived intrinsic barriers to exercise, exercise self-efficacy and physical activity levels of those living with a SCI. The results indicate that peer trainers and student trainers may be equally as effective on knowledge translation, change in perceived intrinsic barriers, and exercise self-efficacy in people with SCI. Furthermore, all participants were seen to improve their level of physical activity participation over the course of this study, regardless of whether they were paired with a peer or a student trainer.

4.1 Physical activity guidelines can be effectively translated and mobilized by SCI peer trainers and student trainers alike

For individuals with SCI, peers have been found to have an important role in many areas of life, such as interpersonal relationships, employment, independence, and social integration/participation (Sweet, Martin Ginis, and Tomasone, 2013, Sweet, Noreau, Leblond and Martin Ginis, 2016, Divanoglou and Georgiou, 2016). Previous studies have also indicated that those living with a SCI prefer peers and health care providers as the preferred messengers for PA communications (Letts et al., 2011). Our evidence suggests that students could be just as effective. When reviewing the interaction with the peer trainers versus student trainers, the translation of the exercise guidelines to our participants was equivalent, suggesting that knowledge translation was equally effective whether delivered by a peer or by a student trainer.

However, it is possible that potential between-group differences could have been missed due to the small sample size.

Other studies have highlighted the need for PA promotion strategies to include a component of interpersonal communication (Salci, Perrier, Ginis, and Martin Ginis, 2016). When considering some of the key topics discussed between our groups, there was quite a bit of overlap and consistency in topics such as exercise, social support and community, suggesting that a trained student can be as effective as a trained peer when disseminating knowledge as it relates to physical activity. Indeed, the average number of meetings over the course of 3 months was comparable between the two groups, although the average duration of the meetings differed quite a bit, with student trainers tending to spend more time than the peer trainers with their participants. Perhaps when engaging specifically in physical activity, a student is able to be more of a personal trainer than a supporting peer.

Mobilization of physical activity guidelines was also similar between groups. Most participants, regardless of who they were paired with, dramatically improved their total physical activity participation level by the end of the study. This is promising, as the sustainability of PA participation is a critical issue when assessing the longer-term effects of an intervention meant to change exercise behaviour (Gainsforth, et al., 2013, Salci, et al., 2016, Latimer-Cheung, et al., 2013). To date, there have been no studies comparing the effectiveness of peers vs. students within the SCI population as it relates specifically to exercise. There has been one study in older adults that showed that exercise retention was comparable or better in the student groups vs. the peer groups (Dorgo et al. 2009; 2011; 2013); our results also reflect this.

Notwithstanding the small sample size, it is also possible that we did not see any significant outcomes because participants were equally satisfied to meet with student trainers as they were to meet with SCI peer trainers. Participants were blinded at enrolment to the fact that they would be randomly assigned to either the peer or student trainer group to avoid pre-conceived expectation regarding the saliency of their pairing. This may have muted potential differences between groups. Participants were not informed about the two groups until the exit interview. When questioned at the close of the study regarding whether participants felt their experience would have been different had they been randomly assigned to the other group, most participants were satisfied with their pairing and the intervention they received. The lack of difference between groups could also be attributable to the fact that all participants who volunteered for this study could be considered 'intenders', with the interest and motivation of becoming more active. When considering many of the models used to assess behavioural mediation, contemplation or intention is a key predictor for physical activity interventions because it marks a readiness for change in people (Martin Ginis et al., 2013, Latimer-Cheung et al., 2013, Sweet et al., 2016). Often, people who are motivated to participate in a PA study, will have an effect from the intervention (Baranowski et al., 1998).

4.2 The SCI population face many barriers to exercise

People living with a SCI face multiple challenges and barriers post injury in all facets of life and accessing physical activity is no exception (Martin Ginis, Jorgensen, and Stapleton, 2012, Fekete and Rauch, 2012). Common barriers include extrinsic factors, such as the built environment, accessible facilities or equipment, cost and transportation. Intrinsic barriers can include knowing where and how to exercise along with psychosocial barriers such as pain, fear and fatigue (Jarsma et al., 2016).

4.2.1 Intrinsic barriers are the hardest to face

In a systematic literature review looking at correlates and determinants of PA in persons with a SCI, intrapersonal factors such as lack of energy, motivation and pain were the most common barriers and found to have an inverse relationship with PA (Scelza et al., 2005, Gutierrez, Thompson, and Kelp, 2007, Fekete and Rauch, 2012). Our findings are consistent with this as we saw that lack of energy was identified as a barrier by 5/10 participants and pain was listed as a barrier by 6/10 participants at intake. Both lack of energy and pain were still identified by 4/8 participants at the exit interview. Although physical activity participation can directly affect these emotional and psychosocial barriers as well as decrease depression and anxiety (Tawashy, Eng and Lin, 2009, Gioia, Cerasa, and Di Lucente, 2006), and increase life satisfaction and quality of life (Tasiemski, Kennedy and Gardner, 2005, Ditor, Latimer-Cheung, and Ginis, 2003, Martin Ginis, Jetha, Mack, and Hetz, 2010), this was not necessarily an area that peer or student trainers could impact through social support, and unfortunately, once a secondary health concern has occurred, such as pain, urinary tract infections, pressure sores, or a respiratory infection, it will inevitably prevent someone from participating in PA (Kehn and Kroll, 2009).

One key intrinsic barrier identified that we could target with this intervention was lack of training or education, or knowing where to go to exercise (Rimmer et al., 2004). It seems we were able to address this barrier in both groups since we saw this barrier reported by 6/10 participants at intake, but it was no longer identified as a barrier by any participant at the exit interview. It seems that our intervention could also target motivation. Lack of motivation was one of the most prominent intrinsic barriers (identified by all participants at intake), but was reported by only 3 participants at the exit interview.

Despite motivation and interest in being active, people with SCI face many more barriers compared to the able-bodied population. This could shed light on why all of our participants except one were meeting the recommended PA guidelines for SCI post intervention, but still listed emotional/psychological factors as their top reported barriers at the exit interview. As our peer and student training did not specifically provide techniques that address these areas, we were not surprised by this finding. Addressing these intrinsic barriers, coupled with health promotion and social support is vital for increasing physical activity levels and reducing the risk of secondary health conditions.

4.2.2 Examining the extrinsic barriers: Is it all in the environment?

Self-determination theory (SDT) is a theory based on human motivation and wellness (Deci and Ryan, 2008). This theory supports the notion that factors that enhance self-motivation and well-being are in fact housed in social conditions and environments, contexts that provide autonomy, competence and relatedness (Ryan and Deci 2000). This is an interesting area that needs further investigation, specifically as it relates to PARC as our site of intervention. PARC's facilities and operational model facilitate PA by providing a positive social environment, and accepting only participants living with paralysis due to a SCI. This environment could in turn fulfill the need for relatedness and seeing others similar to oneself modeling positive exercise behaviours. Therefore, regardless of whether a participant is paired with a peer or student trainer, PARC's environment in itself may already provide the crucial motivational stimulus for promoting engagement in PA among our participants.

Community peer-based programs have been found to be successful based on three key themes: 1) a unique learning environment; 2) a unique learning resource who offers relatedness and empowerment; and 3) and an intervention that meets the needs of the population (Divanoglou & Georgiou, 2016). However, our results here seem to suggest that by meeting the first and third of the above-listed themes, the medium for delivering the intervention does not necessarily need to be a SCI peer trainer (offering the aspect of relatedness). One consideration is that although our student trainers are still students, they are training to become health care providers, which are also identified as a preferred messenger (Letts et al., 2011). As our student trainers within this study were all kinesiology students, it can be assumed that they bring particular background knowledge as it relates to exercise physiology, strength and conditioning and human motor behaviour. Moreover, all students were already active volunteers within PARC and therefore had immeasurable exposure to and interactions with those living with a SCI as it relates to adapted and modified exercise. Therefore, it is possible that our student trainers were regarded as being equally capable of tailoring an individual exercise routine and therefore able to empower the participants to address their barriers and physical limitations to physical activity.

4.3 If exercise self-efficacy is the key, why don't we see it?

Although self-efficacy is one of the most commonly researched concepts as it relates to exercise and other health promotion activities, and has been identified as a direct determinant of behaviour (Bandura, 1997), very few studies have been done on exercise self-efficacy and persons with a spinal cord injury (Kroll et al., 2006). Those that have been done are primarily cross-sectional and did not examine exercise self-efficacy as a mediator of exercise behaviour. Specifically, Kroll et al., (2012) found that self-efficacy, after controlling for demographics and clinical characteristics, was the only independent variable that predicted exercise outcomes such as frequency and intensity of resistance and aerobic training. Similarly, when Nooijen et al., (2015) explored the relationship between exercise self-efficacy and physical capacity, they found those with better fitness (as measured by power output of a wheelchair based accelerometer) had a higher belief in their ability to exercise. However, to our knowledge, this study was the first to use an intervention with the specific aim to affect exercise self-efficacy in persons with SCI.

An interesting finding in our study was that exercise self-efficacy seemed to decrease in most participants after their initial meeting with their peer/student trainer. Thereafter, ESES scores increased again, but did not surpass that recorded at baseline, although the level of physical activity increased. This was a surprising finding because the literature to-date suggested that as ESES increases, so should physical activity levels in people with SCI (Kroll et al., 2012). On the other hand, a systematic review of 25 PA interventions and 45 PA correlational studies among the general able-bodied population found that although the specific aim of most studies was to change physical activity behaviour, most interventions actually had little or no impact on actual PA levels (Baranowski et al., 1998). However, of those studies that did report changes in PA behaviour, less than 30% of them could actually attribute their effects to the theoretical concept underlying their intervention. As reviewed earlier in this thesis, many of the theoretical frameworks developed to enact behavioural change center on self-efficacy. Our findings are then consistent with Baranowski's findings. Perhaps people motivated enough to participate in intervention studies will see an increase in their activity, regardless of their level of self-efficacy. Thus, interventions to improve physical activity behaviour in people with SCI may be better directed towards addressing the multiple barriers to exercise they face, assuming that they are already well motivated to enhance their leisure time physical activity.

Chapter 5: Methodological considerations

In our study, we had the advantage of conducting our work in a unique exercise facility that was designed to address some of the most common extrinsic barriers to physical activity in SCI – the physical (built) environment (Rimmer et al, 2005). PARC is staffed with knowledgeable staff and volunteers, the equipment is specifically designed for wheelchair use and the building and centre design is congruent to moving around and within equipment while using a manual or motorized wheelchair. Another advantage is that the facility is free to use and therefore cost is not a barrier. Unfortunately, these characteristics are not typical of community fitness centers (Rimmer et al., 2004, Rimmer et al., 2005, Arbour & Ginis, 2011), and therefore the results of this study may have limited generalizability to usual community settings.

Previous studies have indicated that in fact, allowing for an open, individualized approach, as opposed to prescribing a specific protocol for delivery, is the most effective means of translating the PA guidelines (Letts et al., 2011). This allows the peer or student trainer to respond to the individual needs of the participants and adopt an individualistic approach (Boschen et al., 2003). In our study, there was no prescribed frequency or duration of the one-to-one interactions between the peer/student trainers and the participants, other than the initial meeting. This meant that after the first meeting, peer/student trainers and participants only met if they wished to, resulting in some pairs meeting more often than others. We saw a range in the number of times the pairs met and the duration of those meetings. It is possible that the variations in meeting frequency and duration resulted in varying levels of perceived social support and possible exercise self-efficacy. Unfortunately, with the small sample size, we were unable to undertake further analysis to understand the impact of this variation.

Although the LTPAQ-SCI has been shown to be a valid and reliable measure of physical activity (Ginis et al., 2012), it is still a self-reported measure and often PA levels can be overrepresented in self-reports (Colley et al., 2011; Troiano et al., 2008). Also, moderate PA may be unaccounted for during daily activities of living which are not perceived as true moderate intensity activity, such as making transfers, navigating environmental barriers, preparing meals, changing sheets, and ascending a ramp (Janssen, van Oers, van der Woude, and Hollander, 1994). Moreover we administered the questionnaire at certain time points during the intervention. Participants often noted that certain weeks were better than others depending on secondary health concerns, weather and overall energy levels. A more sensitive method of measuring PA levels could be through the use of accelerometers. Indeed, evidence shows that there is a lack of relationship between self-reported PA and actual PA measured by an accelerometer (Tanhoffer et al., 2012; van den Berg-Emons et al., 2011). Considering this, we may have missed some finer differences in physical activity participation between the groups although the LTPAQ still enabled us to detect gross changes in PA over the course of the study.

Many personal characteristics can also affect an individual's ability to change a behaviour, such as physical activity. Hampton and Nan (2004) explored the joint contributions of demographic variables such as age, time of injury, income, statuses of employment, and marriage, as well as self-efficacy and perceived social support in people with an SCI. Their results showed that age at injury could significantly account for variance in physical activity behaviour, along with general self-efficacy and social support. This has been more recently refuted by a systematic review by Fekete and Rauch (2012), showing that many of these variables, such as marital status and income have not been associated to PA in SCI, and that gender is only weakly associated with PA. One personal factor that has been reported to have an effect specifically on fitness and recreation in people with SCI is time post-injury (Fougeyrollas and Noreau, 2000). Our evidence is consistent with this in that 2 of the 3 participants who had only been living with a SCI for 1 year or less had the highest number of total minutes of physical activity after 12 weeks. This may suggest the need for further investigation into the optimal time to translate PA guidelines for SCI and when is a good time to start addressing exercise behaviour.

It is possible that the relatively short timeframe of our intervention period (3 months) could impact our ability to observe measurable changes in our outcomes. However, results from other studies that have used a longer timeframe, such as 9 months, already showed significant differences in physical activity levels and its effects within the first 3 months of the intervention (Hicks et al., 2003; Dorgo et al., 2011).

Finally, this study looked at physical activity behaviour during the winter months of Vancouver, BC. Although we generally have a milder climate than the rest of Canada, this year brought an abundance of snow resulting in cold temperatures and snow covered sidewalks and streets. Although this may not have impacted indoor activity, many participants mentioned their limited ability to leave their houses during these weeks.

5.1 Conclusions and future directions

It is clear that physical activity is the key to increasing independence, quality of life, and functional mobility while mitigating several secondary health concerns in people with a SCI (Boschen et al., 2003; Latimer-Cheung et al., 2013), yet less than 50% of those who express interest in exercise are doing so (Scelza et al., 2005). By focusing on the physical activity guidelines and exercise self-efficacy (the motivating factor for changing exercise behaviour) this study attempted to address the main intrinsic barriers to exercise participation (Scelza et al., 2005; Ginis et al., 2011). Our evidence shows that the Active Living Leaders Training Program is an effective tool for providing knowledge and tools to both peer trainers and student trainers looking to support increasing LTPA in people with a SCI. Practical implications from this suggest that student trainers are a viable delivery agent for PA knowledge and mobilization. Further, the availability of eligible student trainers may be greater than SCI peers, particularly considering our stipulation that trainers had to be meeting recommended PA guidelines. On a policy level, when developing staffing plans at community centres or gyms, the Active Living Leaders Program is a readily available resource that can be exploited to ultimately increase the reach of PA interventions.

This study also supports the importance of having a facility that addresses the extrinsic barriers facing those living with an SCI who want to exercise, creating greater opportunity and accessibility. As discussed above, our results were very likely influenced by the specialized setting of PARC as our intervention site. Future studies are warranted to understand the differential effects of peers vs. student trainers in usual community settings.

Although the sample size was small, the information gained from this study indicates that SCI-specific exercise programs supported by leadership models (whether led by peer or student trainers) may be equally effective in promoting exercise participation in individuals with SCI. This will only become more important in the future as there is emerging evidence that the current PA guidelines for SCI may be inadequate for improving biomarkers of cardiovascular disease risk (de Zepetnek, Pelletier, Hicks, MacDonald, 2015). This indicates that modifications to the guidelines are likely required to improve the potential for cardiovascular protective benefits. Based on the subjective PA data compiled in this study, all but one of our SCI participants exceeded the SCI physical activity guidelines of 40 minutes/week by the end of the intervention.

Should the guidelines increase it will only be more challenging for those living with SCI to meet the recommendations. In the long run, we hope that such interventions can help to mitigate the risks of immobility related secondary health concerns and improve overall quality of life among the SCI population.

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Appendices

Appendix A

MEMBERSHIP FORM

ALL INFORMATION WILL BE KEPT STRICTLY CONFIDENTIAL

Surname: ______________________________ First Name: _________________________

Address: ____ City:__________________

Prov: _____________________________ Postal Code: ____________________________

Phone: (H) _______________________ (C) _____________________________________

Email :__________________________________

Date of Birth: _______________________________ M ☐ F ☐

What month and year were you injured? ____________________________________

Level of injury ___________ ASIA __________

Sensory: Partial ☐ Full ☐ None ☐

Motor: Complete ☐ Incomplete ☐

Current Living Arrangements: Single ☐ Family ☐ Spouse/Partner ☐

Method of Transportation: Public ☐ Family ☐ Own Vehicle ☐

Income/Financial Support: Disability Pension ☐ Insurance ☐ Employed ☐

Do you experience any of the following?
___Chronic pain
___Fatigue
___Autonomic Dysreflexia
___Orthostatic Hypotension

Any other medical conditions (for example, high blood pressure, diabetes, heart disease, etc.)?

Yes___ No___

If yes, please specify: ___________________

Are you currently taking any medications? If so, please list
____

What is your current level of exercise/physical activity?

____Sedentary ____Exercise/physical activity 1-2x per week
____Exercise/physical activity 3-4x per week ____Exercise/physical activity >4x per week

On those days, how many minutes do you usually spend exercising/being active?

____

From the list provided below, please select the barriers that prevent you from exercising

(please check top three).

____Lack of time
____Lack of energy
____Do not know how to exercise
____Lack of education/training
____Lack of motivation
____Lack of transportation
____Cost of exercise program
____Do not know where to exercise
____Lack of accessible equipment
____Lack of interest
____Health conditions prevent exercising
____Exercise will not help my condition
____Exercise is too difficult
____Pain prevents me from exercising
____Other____________________________________

Please answer the following questions:

1. Have you heard of SCI Action Canada?

   Yes ☐ No ☐

2. Have you heard of any physical activity guidelines for people with a SCI?

   ☐ ☐

Yes No

→ If you **have** heard of guidelines, how much physical activity did the guidelines recommend?

How do you prefer to communicate?
____Phone ____Email ____Text
____Video conference ____Other: ________________

Appendix B

Knowledge Translation Checklist:

1. Did the peer discuss the Physical Activity Guidelines for SCI?

Yes ☐ No ☐

2. Were the guidelines explained correctly?

Yes ☐ No ☐

If no, which guidelines were missed/incorrect? (Please circle)

- Strength training (how often – 2 times per week)
- Strength training (how much – 3 sets of 8-10 reps)
- Strength training (how hard - With a resistance that is heavy enough that you can barely, but safely, finish 8-10 repetitions of the last set)
- Aerobic exercise (how often – 2 times per week)
- Aerobic exercise (how much – 20 minutes)
- Aerobic exercise (how hard – moderate to vigorous intensity)

3. Did the peer discuss different ways to engage in strength training?

Yes ☐ No ☐

4. Did the peer discuss different ways to engage in aerobic activity?

Yes ☐ No ☐

5. Did the peer discuss the benefits of physical activity?

Yes ☐ No ☐

If yes, what benefits were mentioned?

____

6. Did the peer discuss other ways of being physically active (such as sports or downtime)?

Yes ☐ No ☐

If yes, what was mentioned?

____

____

7. Any other topics or suggestions/ideas that the **peer** discussed:

____

____

____

____

8. Any other topics or suggestions/ideas that the **participant** discussed:

____

____

____

____

Appendix C

Date:	Method:	Time Spent:	Topics discussed:	Comments:
	☐ Over the Phone ☐ In Person (group) ☐ In Person (one on one) ☐ Online (email) ☐ Online (video)		☐ SCI Guidelines ☐ Exercise Barriers ☐ Exercise Opportunities ☐ Sports/Activities ☐ Transportation ☐ Health Concerns	Other topics discussed:
	☐ Over the Phone ☐ In Person (group) ☐ In Person (one on one) ☐ Online (email) ☐ Online (video)		☐ SCI Guidelines ☐ Exercise Barriers ☐ Exercise Opportunities ☐ Sports/Activities ☐ Transportation ☐ Health Concerns	Other topics discussed:
	☐ Over the Phone ☐ In Person (group) ☐ In Person (one on one) ☐ Online (email) ☐ Online (video)		☐ SCI Guidelines ☐ Exercise Barriers ☐ Exercise Opportunities ☐ Sports/Activities ☐ Transportation ☐ Health Concerns	Other topics discussed:

Appendix D

KT PARC Satisfaction Questionnaire

Thank you for participating in our 12-week KT physical activity study. In order to better understand your experience in this study and how we could improve for future participants, kindly complete this questionnaire to the best of your ability.

1. I enjoyed participating in this study

Disagree	1	2	3	4	5	6	7	8	9	10	Agree

2. I would participate in this study or a similar study again

Disagree	1	2	3	4	5	6	7	8	9	10	Agree

3. I would recommend this study to other PARC participants

Disagree	1	2	3	4	5	6	7	8	9	10	Agree

4. I feel that my aerobic fitness has improved because of this study

Disagree	1	2	3	4	5	6	7	8	9	10	Agree

5. I feel that my muscle strength has improved because of this study

Disagree	1	2	3	4	5	6	7	8	9	10	Agree

6. I felt that the peer and/or student trainers were effective

Disagree	1	2	3	4	5	6	7	8	9	10	Agree

7. I felt comfortable interacting with my KT peer/student trainer

Disagree	1	2	3	4	5	6	7	8	9	10	Agree

8. At the beginning of this study, you listed 3 barriers to exercise. To what degree do you feel that these barriers have been addressed?

Not at all 1 2 3 4 5 6 7 8 9 10 Fully

9. Now that the study is complete, what are the barriers that prevent you from exercising? (please check top 3).

____Lack of time

____Lack of energy

____Do not know how to exercise

____Lack of education/training

____Lack of motivation

____Lack of transportation

____Cost of exercise program

____Do not know where to exercise

____Lack of accessible equipment

____Lack of interest

____Health conditions prevent exercising

____Exercise will not help my condition

____Exercise is too difficult

____Pain prevents me from exercising

____Other______________________________

10. The best thing about participating in this study was:
____
____

11. If I could change one thing from this study, it would be:
____
____

12. If you had been randomly assigned to the other group, how do you think this would have affected your experience?
____
____
____

Appendix E

Physical Activity in SCI Knowledge Acquisition Questionnaire (SCI-KAQ)

1. How often should someone with a SCI engage in strength training exercise?

- Two times per week - at least
- Two times every other day
- Two exercises per muscle per day
- Two times only after doing aerobic activity

2. How often should someone with a SCI engage in aerobic exercise?

- Two times per day
- Two times per hour
- Two times per month
- Two times per week

3. How much strength training should one engage in?

- 3 sets of 8-10 repetitions for each major muscle group
- As much as you can lift
- 3 sets of 15 - 20 repetitions only

○ 150 kg on the bench press every time

4. How much aerobic activity should one engage in?

○ At the most 20 minutes of activity per day

○ At least 20 minutes of daily living activity per day

○ At least 20 minutes of aerobic activity during each workout session

○ At the most 20 minutes of aerobic activity a week

5. How hard should you engage in strength training activity?

○ With a resistance that is heavy enough that you can barely, but safely, finish 8-10 repetitions of the last set

○ As hard as possible, you only do it once anyway

○ Depends on the resistance you can find, and you are to do it for as much as you can

○ Pick a resistance not too heavy so that you are not too tired at the end of 8-10 repetitions of the last set

6. How hard should you engage in aerobic activity?

○ Moderate to vigorous intensity

○ Vigorous intensity through out

○ At a pace that is slow and steady

○ Mild to moderate at all times

7. How can you engage in strength training?

- Free Weights
- Elastic resistance band
- Weight Machines
- Household Items
- A and C only
- All are correct

8. How can you engage in aerobic activity?

- All are correct
- Upper body activities such as wheeling
- Lower body activities such as cycling
- Whole body activities such as recumbent stepper
- None are correct
- All are correct

9. What can a person expect in aerobic benefits if they meet the aerobic activity recommendations?

- An improvement in cardiovascular endurance
- Decreased level of fatigue when active
- Increased mobility

- All are correct
- None are correct

10. Moderate intensity activities should be easy to complete and you should be able to maintain them for at least 2 hours.

- True
- False

11. Sport for people with disabilities is only for people who are already fit, and skilled, and that want to go to the Paralympics.

- False
- True

12. The best way to start participating in a new sport is to...

- Take your time, and learn the skills needed in small increments
- Only start after you know all the skills needed
- Participate when you are good enough to score a lot of goals
- All answers are correct

13. Making a plan for participation can increase confidence for staying involved in a sport or exercise

- True
- False

14. Down time can be physical activity time?

- True
- False

15. Physical activity may...

- All answers are correct
- Reduce some of my pain
- Make me feel more energized
- Be easier than I thought with more adapted facilities and equipment
- None are correct

Appendix F

SCI Exercise Self-Efficacy Scale

Please tell us how confident you are with regard to carrying out regular physical activities.

I am confident. . .

	Not at all true	Hardly true	Moderately true	Exactly true
1. …that I could always overcome barriers and challenges with regards to exercise if I try hard enough.	☐	☐	☐	☐
2. … that I could find the means and ways to exercise and be physically active.	☐	☐	☐	☐
3. …that it is easy for me to accomplish my activity and exercise goals	☐	☐	☐	☐
4. …that when I am confronted with a barrier to exercise I could usually find several solutions to overcome this barrier.	☐	☐	☐	☐
5. …I could exercise even when I am tired.	☐	☐	☐	☐
6. …I could exercise even when I am feeling depressed.	☐	☐	☐	☐
7. …that I could exercise even without the support of my family or friends.	☐	☐	☐	☐
8. …that I could exercise without the help of an exercise therapist.	☐	☐	☐	☐
9. …that I could be physically active despite my spinal cord injury.	☐	☐	☐	☐
10. …that I could exercise even if I had no access to a gym or training facility.	☐	☐	☐	☐

Appendix G

Leisure Time Physical Activity Questionnaire for People with Spinal Cord Injury

(LTPAQ-SCI)

INSTRUCTIONS: I am going to ask you about the time you spent engaging in mild, moderate, and heavy intensity LTPA in the last 7 days. Leisure Time Physical Activity (LTPA) is physical activity that you choose to do during your free time, such as exercising, playing sports, gardening, and taking the dog for a walk (necessary physical activities such as physiotherapy, grocery shopping, pushing/wheeling for transportation are not considered LTPA). Please refer to the intensity chart (next page) for descriptions of what mild, moderate and heavy intensity LTPA feel like.

1. Mild intensity LTPA 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…

   During the last 7 days, on how many days did you do mild intensity LTPA? _______

   On those days, how many minutes did you usually spend doing mild intensity LTPA? ______

2. Moderate intensity LTPA 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…

   During the last 7 days, on how many days did you do moderate intensity LTPA? _______

   On those days, how many minutes did you usually spend doing moderate intensity LTPA? ______

3. Heavy intensity LTPA requires a lot of physical effort. Heavy intensity 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.

   During the last 7 days, on how many days did you do heavy intensity LTPA? _______

   On those days, how many minutes did you usually spend doing heavy intensity LTPA? ______

	NOTHING AT ALL	**MILD**	**MODERATE**	**HEAVY**
How hard are you working?				
	• Includes activities that even when you are doing them, you do not feel like you are working at all.	• Includes physical activities that require you to do very light work. You should feel like you are working a little bit but overall you shouldn't find yourself working too hard	• Includes physical activities that require some physical effort. You should feel like you are working somewhat hard but you should feel like you can keep going for a long time.	• Includes physical activities that require a lot of physical effort. You should feel like you are working really hard (almost at your maximum) and can only do the activity for a short time before getting tired. These activities can be exhausting
How does your body feel?				
Breathing & Heart rate	Everything is normal	• Stays normal or is only a little bit harder and/or faster than normal	• Noticeably harder and faster than normal but NOT extremely hard or fast	• Fairly hard and much faster than normal.
Muscles		• Feel loose, warmed-up and relaxed. Feel normal temperature or a little bit warmer and not tired at all	• Feel pumped and worked. Feel warmer than normal and starting to get tired after awhile.	• Burn and feel tight and tense. Feel a lot warmer than normal and feel tired.
Skin		• Normal temperature or is only a little bit warmer and not sweaty	• A little bit warmer than normal and might be a little sweaty	• Much warmer than normal and might be sweaty
Mind		• You might feel very alert. Has no effect on concentration	• Require some concentration to complete	• Requires a lot of concentration (almost full) to complete