Considerations for a Targeted Self-Management Program for Individuals with Traumatic Spinal Cord Injury

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy

Institute of Health Policy, Management & Evaluation
University of Toronto

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Abstract

Evidence points to the need for increased self-management support efforts to reduce secondary complications in spinal cord injury (SCI). The overall objective of this thesis was to understand the phenomenon of self-management in individuals with traumatic SCI, and then based on this understanding; determine the implementation considerations for a targeted self-management program. This thesis used a mixed methods approach with an exploratory design. Twenty-six interviews across three stakeholder groups were conducted in Phase I. In the first paper (qualitative), the following five facilitators to self-management were identified: physical support from the caregiver, emotional support from the caregiver, peer support and feedback, importance of positive outlook and acceptance, and maintaining independence. The following five barriers to self-management were identified: caregiver burnout, funding and funding policies, lack of accessibility, physical limitations and secondary complications, and difficulties achieving positive outlook or mood. In the second paper (qualitative), the meaning of self-management among the SCI and caregiver participants related principally to internal
responsibility attribution. For the manager participants, the meaning was much narrower and the overarching theme of internal responsibility attribution that was observed among the SCI-caregiver dyads was not as widely expressed by this group. These findings informed the development of a survey that was administered nationally to individuals with traumatic SCI (n=99). In the third paper (quantitative), the components of a tailored self-management program were identified and included the preference for an internet-based program. The final paper examined the association between psychological characteristics in self-management and depression status in individuals with a traumatic SCI. Lower self-efficacy and mastery scores, as well as less time since injury, were associated with depression status. These findings could be used for the development, pilot-testing, and evaluation of a targeted self-management program for individuals with traumatic SCI.
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Related Publication

Chapter 1
Background, Conceptual Frameworks & Research Objectives

1.1 BACKGROUND

1.1.1 Description and Epidemiology of Traumatic Spinal Cord Injury

There are two main mechanisms of spinal cord injury (SCI), either traumatic or non-traumatic. Non-traumatic SCI includes etiologies that do not involve a traumatic mechanism of injury and includes conditions such as vertebral spondylosis, tumour compression, vascular ischemia, neuronal motor disease, infectious abscess, and traverse myelitis (McKinley et al., 1999). Traumatic SCI relates to a traumatic mechanism of injury, with the most common causes identified as falls, motor vehicle collisions, or having been struck by an object (Couris et al., 2010). Individuals with traumatic SCI are the focus of the current thesis. The age-adjusted incidence of traumatic SCI among adults in Ontario is approximately 23.1 per million (95% confidence interval: 20.2-26.3) (Couris et al., 2010). Traumatic SCI often occurs in a younger male population, usually during the most active and productive time of the individual’s life (Maharaj, 1996; O’Connor, 2001; Couris et al., 2010). Among incident cases in Ontario, the mean age was 51.3 (standard deviation=20.1) and 74.1% of the sample was male.

1.1.2 Spinal Cord Injury and Secondary Complications including Depression

A SCI results in a number of motor, sensory, and autonomic impairments which predisposes a person to multisystem dysfunction, leading to an increased likelihood of a range of related secondary complications (Berkowitz, 1993; Savic et al., 2000; Cardenas et al., 2004; Paker et al., 2006), defined as medical consequences that can cause functional limitations (Noreau et al., 2000). A cross-sectional study from the US Model System conducted by Anson
and Shepherd (1996) determined that 95.6% of patients had at least one medical complication at the time of their routine annual check-up. Common secondary health complications after SCI include pressure ulcers, urinary tract infections, bowel problems, fractures, chronic pain, and depressive disorders (Noreau et al., 2000). Depression or significant depressive symptomology is the most common psychological condition associated with SCI, affecting approximately 25% to 30% of individuals with SCI living in the community (Craig et al., 2009). The presence of depression in SCI is associated, in turn, with a variety of poorer outcomes including increased hospitalization periods and (other) secondary medical complications as well decreased self-care dependency (Elliot & Frank, 1996; Elliot & Kennedy, 2004). Despite the fact that many of these complications are amenable to treatment and/or prevention, overall, secondary complications represent a significant burden at both the individual and health system level: they intensify the experience of disability for people with SCI by negatively impacting long-term health, productivity/employment, dignity, mobility, and independence (Post & Noreau, 2005), and they are costly, in terms of using limited health care resources (direct and indirect costs) (Dryden et al., 2005; Dorsett & Geraghty, 2008; Munce et al., 2013).

1.1.3 Spinal Cord Injury and Secondary Complications and Health Care Utilization

As a result of secondary complications, individuals with SCI have greater rates of contact with the health care system than the general population, and also have multiple rehospitalizations throughout their lifetime. For example, Dryden and colleagues (2004) found that compared with a control group, individuals with SCI required 30 more hours of home care services, were 2.7 times more likely to have physician contact, spent 3.3 more days in hospital, and were rehospitalized 2.6 times more often. Rehospitalization following SCI has been studied in a number of countries including the US, Britain, Australia (Middleton et al., 2004), the
Netherlands (Bloemen-Vrencken et al., 2007), Italy (Franceschini et al., 2003), and Turkey (Paker et al., 2006). These studies have reported that approximately one-third of persons with a traumatic SCI will be rehospitalized each year (Ivie & DeVivo, 1994). More recently, Jaglal and colleagues (2009) reported a similar readmission rate of 27.5% among individuals with traumatic SCI in Ontario. Secondary complications were the main reasons for readmission. In a related study, a high number of visits to family physicians and physiatrists were reported (Munce et al., 2009). Factors predicting 50 or more visits to all types of physicians included patient age 70 years or above, direct discharge to chronic care, and in-hospital complication. Age 70 years or less and direct discharge to chronic care were associated with 50 or more visits to specialists. Rurality predicted high emergency department visits (Munce et al., 2009). Our research team concluded that the high rate of physician and specialist utilization, emergency department visits, and hospital readmissions indicate that current care practices are not managing or preventing secondary complications adequately. The implications of these findings are that future research should examine preventive strategies that could be implemented in order to improve the long-term quality and cost of care for persons with traumatic SCI (Jaglal et al., 2009; Munce et al., 2009). There are a variety of factors at play that can increase the risk of secondary complications and subsequent high health care use (as described below), increasing the need for such preventive strategies.

1.1.3.1 Contributing Factors to Secondary Complications and High Health Care Use

As the length of time in rehabilitation declines due to increasing costs (Rowland et al., 2006), less time is available for physical recovery, psychological adjustment, and education in how to cope with a changed health state. Many of those injured may not have had time to absorb adequate information about how to care for themselves, nor how to adapt to the health-related
challenges that they will face. As such, individuals with SCI may feel emotionally and psychologically unprepared to return home at discharge. Also, as a result of this shortened length of stay, individuals return to their communities before their homes have been modified (Pollack et al., 1992). Relatedly, families and others comprising the informal support network for individuals with SCI also have less time to adjust. As a result, there is some evidence to suggest that these reduced lengths of stay in rehabilitation, and ensuing consequences, lead to higher rates of secondary complications and subsequent high rehospitalization rates (Jones & Evans, 1998). Rowland and colleagues (2006) argue that this phenomenon highlights the importance of educating individuals with SCI about their medical conditions, including how to prevent secondary complications.

Furthermore, as a result of the relatively low prevalence of individuals with SCI, few primary health care professionals have individuals with SCI in their practice. Consequently, they do not often have much opportunity to gain sufficient knowledge and experience about the specific care these patients need (Bloemen-Vrencken et al., 2005). This may lead to improper management and increased likelihood of secondary complications, and subsequent high (inappropriate) health care utilization. Relatedly, access to and availability of services also represent other contributing factors to inappropriate health care use. For example, in the study by Munce and colleagues (2009), as described above (see section 1.1.3), rurality was associated with higher emergency department visits, pointing to the limited accessibility to/availability of primary care services for SCI patients in rural regions.

Lastly, SCI is not conceived of as a chronic condition, which may explain the lack of self-management programs specifically for individuals with SCI. However, as progress in medical and rehabilitation treatment has improved, patients with more complex needs are
surviving (Vaidyanathan et al., 1998), with the mean survival rate after spinal cord trauma exceeding more than 30 years (DeVivo et al., 1999). Thus, the future implementation of a preventive strategy/intervention, such as a self-management program, could be one approach to address these complex needs.

1.1.4 Previous Interventions to Improve Secondary Complications

A systematic review of follow-up care programs for individuals with SCI living in the community, with the specific intention to reduce/prevent secondary impairments and subsequent hospital readmission, revealed five main types (Bloemen-Vrencken et al., 2005). These included 1) telemedicine (i.e., the use of telecommunications technology that either delivers or supports the delivery of health services and education via long distance) (Phillips et al., 1998; 1999; Mathewson et al., 1999; 2000; Weinel et al., 2000; Phillips et al., 2001); 2) outpatient consulting hours (i.e., providing physicals, reviews of daily functioning, and support in case of health problems) (Remington et al., 1991; Dover et al., 1992; Barber et al., 1999; Lapierre et al., 1999; Dunn et al., 2000; Ferguson et al., 2000); 3) home visits (Jones, 1972; Fine et al., 1978; Beer, 1984); 4) case management (i.e., involving the coordination of care within, between, and beyond the acute and rehabilitation programs, extending care and coordination to the community and managing the reemerging needs of the population over time (Cioschi & Goodman, 1994); and, 5) miscellaneous types of follow-up care consisting of outpatient consulting hours, home visits, peer teaching and support, therapy from several care disciplines, SCI education, providing SCI expertise and support to community health care providers, and coordination of care with community nursing agencies (Steinberg, 1975; Dinsdale et al., 1981; Warner & Taylor, 1982; Duci & Saperstein, 1986; Brown et al., 1987; Pollack et al., 1992; Lathbury et al., 2000; Beck & Scroggins, 2001). A more recent study by Rowland and colleagues (2006) of 71 individuals with
newly diagnosed SCI (i.e., had a traumatic SCI diagnosis within 6 to 18 months of entering the study), analyzed the effectiveness of an Internet assessment and feedback tool in determining secondary condition risk for pressure sores, urinary tract infections, pain, weight gain and deconditioning, and depression, based on individual responses to a knowledge and behavioural questionnaire. The authors determined that there were no differences between the intervention and control groups in terms of the occurrence of these secondary complications at the post-assessment interval.

1.1.4.1 Deficiencies with Previous Interventions

Bloemen-Vrencken and colleagues (2005) concluded that in the studies of follow-up care programs, in general, the quality of the evaluation was low (i.e., evaluations were cross-sectional in design). As a result, and despite the fact that several studies found positive results, the authors concluded that it was not possible to draw conclusions on the effect of follow-up care strategies on the occurrence of secondary complications. Instead, the authors posited that there is the need for the development of follow-up care strategies for the prevention of secondary complications and subsequent high health care utilization. In fact, the need for effective interventions aimed at the prevention of health problems after discharge from acute and rehabilitative care has been reported frequently (Anson & Shepherd, 1996; Ernst et al., 1998; Rawl et al., 1998; Glidden, 1999; Mattson, 1999; Cox et al., 2001). These findings are further underscored in a study by Caliri (2005), which determined that most education programs for (pressure ulcer) prevention are designed for the initial hospitalization and rehabilitation period, and that more emphasis on patients’ responsibilities for prevention after discharge is needed (i.e., community programs that would reinforce pressure ulcer detection and treatment are lacking). However, as was concluded in the study by Rowland and colleagues (2006), knowledge of secondary complications may be
necessary but is not sufficient in modifying risk. Accordingly, Wagner and colleagues (2001) assert that in order to positively affect patient well-being, complex care interventions should necessarily increase patients’ knowledge, as well as skills, and confidence to manage their condition(s), all of which encompass the tenets of a self-management program, which will be discussed below.

1.1.5 Need for Preventative Strategies in the Community

Indeed, current evidence has suggested the need for increased SCI self-management support efforts to reduce secondary complications, including good knowledge of risk and protective factors for secondary complications, skills to minimize risk, self-monitoring and social support, and timely referral to professional health care (Kroll et al., 2007). A recent study of care received, care needs and preventability of secondary complications among persons with long-term SCI living at home reported that there was substantial unmet need (van Loo et al., 2010). Information, psychosocial care, and self-efficacy were areas that needed to be enhanced and the need to explore self-management strategies was recommended. Similarly, Pang et al. (2009) determined that confidence or self-efficacy to manage SCI in many community-living people with SCI is suboptimal. They concluded that rehabilitation of patients with SCI should include self-efficacy-enhancing strategies and that alleviation of depressive symptoms and pain self-management specifically may be important areas for improving disease-management self-efficacy.

1.1.6 The Chronic Care Model and Self-management Support

The Chronic Care Model (CCM) is an evidence-based, conceptual framework that was initially developed by Wagner and colleagues (1999). It identifies the essential components of a health care system that encourage high-quality chronic disease care. These components are the
community, the health system, delivery system design, decision support, clinical information systems as well as self-management support. The system changes support the development of informed, activated patients and prepared, proactive healthcare teams whose interactions become more productive and satisfying around chronic disease. The CCM has guided a number of healthcare organizations to improve their efforts in care for chronic illness. Over 1000 organizations, including approximately 500 community health organizations supported by the Health Resource Services Association’s Bureau of Primary Health Care, have participated in healthcare improvement activities using the CCM framework (Wagner et al., 2001). Most of these organizations have made measureable improvements in the quality of their care. A review of the literature reiterates that the most successful chronic disease improvement strategies are consistent with concepts and components identified in the CCM (Bodenheimer et al., 2002).

In Canada, the CCM has been modified (i.e., the Expanded CCM) to integrate population health promotion into the prevention and management of chronic disease (see Figure 1) (Barr et al., 2003). This integration broadens the CCM by directing additional efforts to reducing the burden of disease, not just reducing the impact on those who have a disease but also by supporting individuals and communities to be healthy. This strategy requires action on the determinants of health as well as delivering high quality health care services. The Expanded CCM supports the intrinsic role that the social determinants of health play in influencing individual, community, and population health. That is, the Expanded CCM facilitates a fundamental shift in understanding about how individual client care fits within the concepts of population health. This new configuration demonstrates clear associations between the health care system and the community. It is an action-oriented model that broadens the focus of practice to work towards health outcomes for individuals, communities, and populations.
The large inner oval of the CCM represents the health system or an individual health care organization. The Expanded CCM includes a porous border between the formal health system and the community. This porous border is a graphical representation of the flow of ideas, resources, and people between the community and health system.

Another area of change in the Expanded CCM is the placement of the four areas of focus: decision support, delivery system design and information systems, and self-management support. The focus of this thesis is on self-management support. These four circles now straddle the border between the health system and the larger community. To address both the delivery of healthcare services and population health promotion, the activities of these four areas can be integrated within, and have an impact on, both the healthcare organization and the community. That is, additional detail is created in the “Community” oval. This integration of population health promotion and clinical treatment also affects the lower half of the model. Furthermore, the Expanded CCM incorporates five action areas of the Ottawa Charter for Health Promotion, specifically, to develop personal skills, re-orient health services, build healthy public policy, create supportive environments, and strengthen community action. In merging these five action areas with the CCM, two of the areas of focus are re-named and re-defined, including the delivery system design/re-orient health services and self-management/develop personal skills, which is discussed below.

The self-management/develop personal skills component of the Expanded CCM refers to the support of self-management in coping with a disease but also to the development of personal skills for health and wellness. In this expanded version, self-management strategies may take place in the community as well as the health system. In population health promotion, supporting personal and social development of individuals and groups is done in part by providing
information and enhancing life skills. It increases options available for individuals to exercise more control over their health and their environments. It includes but goes beyond traditional health education messages, such as those dealing with smoking, nutrition, and physical activity. While traditional health education programs are important, these initiatives often have limited impact on health behaviours and/or long-term health status, as identified above (i.e., section 1.1.3.1) by Rowland and colleagues (2006); therefore, such programs must be broadened to include consideration of the determinants of health (Barr et al., 2003).

Figure 1.1: The Expanded Chronic Care Model (Barr et al., 2003)
1.1.7 Self-management as a Prevention Strategy and the Stanford Chronic Disease Self-management Program

The Institute of Medicine (2001) acknowledged self-management as an important aspect of quality of care, if not the most critical aspect of the CCM. Lorig (1993) defined self-management as “learning and practicing skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition”. Lorig (1993) further emphasized that self-management is not an alternative to medical care. Rather, self-management is “aimed at helping the participant become an active, not adversarial, partner with health care providers”. The Stanford Chronic Disease Self-Management Program (CDSMP) is one of the most validated and widely used programs (Lorig et al., 1999a; 2001). The Stanford CDSMP seeks to provide patients with the self-efficacy and skills to better manage their chronic medical conditions, regardless of specific diagnosis (Lorig et al., 1999a; 2001). Individuals (non-health care professionals) are trained and accredited to a rigorous set of quality standards, with training and course delivery focusing on adherence to protocol to ensure content and delivery fidelity. As such, individuals with personal experience with one or more chronic conditions must successfully complete an intensive, highly scripted, and standardized 4.5-day long training program to become facilitators or lay leaders certified to provide the CDSMP. Pairs of certified facilitators deliver the intervention with the use of a Leaders’ manual (i.e., to ensure consistency of content) to groups of 8-10 participants over 6 weekly sessions. Each session lasts approximately 2 hours, and is delivered in community settings (e.g., church halls).

The CDSMP covers generic topics including: an overview of self-management principles, exercise, pain and fatigue management, relaxation techniques (e.g., guided imagery and breathing exercises), dealing with depression, nutrition, communicating with family and
health professionals, problem solving, and goal setting. Goals should be achieved during the following week, be personally relevant, achievable, challenging, have proximal outcomes, and depend largely upon a person’s own efforts. Participants report back to the group on their achievements at the next weekly session. The format of the course is largely participatory and interactive, with short ‘lectureettes’ to introduce topics, group discussion, problem solving, role plays, and mastery experience (i.e., trying out the skills introduced on the course). Participants are encouraged to apply these generic skills to their own situation. Specifically, participants are taught to use behaviour change “action plans”, to use an organized approach to solving common self-management problems, and are given extensive opportunities to practice these skills and receive feedback on their performance (Jerant et al., 2005).

1.1.7.1 Underlying Theory and its Application to Reducing Secondary Complications and Health Care Utilization

The CDSMP is based on Bandura’s self-efficacy theory, a social cognitive theory that states that the key predictors of successful behaviour change are confidence (self-efficacy) in the ability to carry out an action and expectation that a particular goal will be achieved (outcome expectancy). Self-efficacy is seen as an early step in causal pathways of behaviour change in self-management programmes; increasing self-efficacy is a pre-requisite for behaviour change which, through improved self-management may influence health (e.g., reduce secondary complications) and health care use (i.e., reduce emergency department visits). Specifically, the CDSMP incorporates the mastery experience, role modelling, persuasion, and reinterpretation of physiological and affective states to assist participants in making behaviour changes (Bandura, 1977).
1.1.7.2 Efficacy of the Chronic Disease Self-management Program in a Variety of Chronic Conditions

In the US, randomized controlled trials (RCTs) have found the CDSMP to be effective in improving self-efficacy, use of self-management techniques, physical and psychological health status, and reducing health care utilization among participants with arthritis, lung disease, heart disease, and stroke (Lorig et al., 1999a). A review (Griffiths et al., 2007) of four UK RCTs examining the effectiveness of the CDSMP (Griffiths et al., 2005; Kennedy et al., 2007) and the Arthritis Self-Management Program (Barlow et al., 2000; Buszewicz et al., 2006) reported that self-efficacy improved in all studies, psychological distress improved in three studies (Barlow et al., 2000; Buszewicz et al., 2006; Kennedy et al., 2007) and generic quality of life improved in one study (Kennedy et al., 2007) based on intention to treat analysis. Despite these positive outcomes, the effect sizes were small to moderate and health care utilization remained unchanged. The review itself focused on a limited range of outcomes and thus did not report effectiveness for outcomes such as energy (Kennedy et al., 2007), exercise and relaxation (Barlow et al., 2000; Kennedy et al., 2007), cognitive symptom management (Barlow et al., 2000; Griffiths et al., 2005), and communication skills (Barlow et al., 2000).

In a Cochrane systematic review of 17 RCTs of self-management education programs by lay leaders for individuals with a variety of chronic conditions (e.g., hypertension, heart disease, chronic lung disease, arthritis, stroke, diabetes, chronic back pain, chronic fatigue, mental health and neurological conditions), Foster and colleagues (2007) determined that there was a small, statistically significant reduction in pain (Lorig et al., 1999a; Fu et al., 2003; Lorig et al., 2003; Griffiths et al., 2005; Haas et al., 2005; Kennedy et al., 2007), disability (Lorig et al., 1999a; Fu et al., 2003; Haas et al., 2005), and fatigue (Lorig et al., 1999a; Fu et al., 2003; Lorig et al., 2003;
Griffiths et al., 2005; Haas et al., 2005), and a small, statistically significant improvement in depression (Fu et al., 2003; Griffiths et al., 2005). There was a small (but not statistically or clinically significant) improvement in psychological well-being (Lorig et al., 1999a; Haas et al., 2005; Kennedy et al., 2007), but no difference between groups for health-related quality of life (Griffiths et al., 2005; Kennedy et al., 2007). A statistically significant improvement in self-rated general health was also detected (Lorig et al., 1999a; 1999b; Fu et al., 2003; Lorig et al., 2003; Haas et al., 2005; Kennedy et al., 2007). In terms of health behaviours, there was a statistically significant increase in self-reported aerobic exercise (Lorig et al., 1999a; Fu et al., 2003; Lorig et al., 2003; Kennedy et al., 2007) and a moderate increase in cognitive symptom management (Lorig et al., 1999a; Fu et al., 2003; Griffiths et al., 2005). With respect to health care use, there were no statistically significant differences between intervention and control groups in physician visits (Lorig et al., 1999a; Fu et al., 2003; Lorig et al., 2003; Griffiths et al., 2005; Kennedy et al., 2007). There were also no statistically significant differences before and after the intervention in terms of days spent in hospital (Lorig et al., 1999a; Fu et al., 2003; Lorig et al., 2003; Griffiths et al., 2005; Kennedy et al., 2007). Lastly, self-efficacy showed a small statistically significant improvement (standardized mean difference of 0.30, 95% confidence interval -0.41 to -0.19) (Fu et al., 2003; Lorig et al., 2003; Griffiths et al., 2005; Haas et al., 2005; Kennedy et al., 2007). The authors concluded that in the short-term, lay-led self-management education programs improved health behaviours (cognitive symptom management and self-reported frequency of aerobic exercise), increased self-efficacy to manage symptoms, and had a small impact on health status variables such as depression. It was also concluded that there is currently no evidence of an effect on health care use.
1.1.7.3 Efficacy of the Stanford Chronic Disease Self-management Program (CDSMP) in Multiple Sclerosis: Example of the Use of the CDSMP in a Neurological Condition

Barlow and colleagues (2009) conducted a recent study on the impact of the CDSMP in individuals with multiple sclerosis (MS), and were particularly interested in psychosocial outcomes including self-efficacy and depression, given that some evidence has accrued regarding the effectiveness of the CDSMP for patients with long-term health conditions in reducing anxiety and/or depression (Barlow et al., 2000; Griffiths et al., 2005; Buszewicz et al., 2006; Kennedy et al., 2007) and enhancing positive affect (Barlow et al., 2000). The results of this RCT demonstrated that the CDSMP had an impact in terms of improved self-efficacy and physical health status, with trends toward improvement on depression and MS self-efficacy. Notably, these improvements were maintained at 12-month follow-up. Further, the authors concluded that although the general pattern of results was in the expected direction, effect sizes were small, as previously found in other studies (i.e., Griffiths et al., 2007) and few changes attained statistical significance.

1.1.7.4 Efficacy of the Chronic Disease Self-management Program in Spinal Cord Injury

Hirsche and colleagues (2011) recently conducted a qualitative study on the experiences of individuals with neurological conditions, including stroke, MS, and SCI, who participated in the CDSMP. As the authors themselves noted, this study represented the first study to examine the experience or the effect of the CDSMP for individuals with SCI. The authors found that the participants with SCI reported the least satisfaction with the CDSMP. Individuals with SCI as well as some of the facilitators suggested assembling a SCI-focused group (e.g., individuals with SCI needed information specific to and modules adopted for being in a wheelchair/reduced mobility). They also found that when some self-management tasks are done by others (as is the
case in individuals with SCI), a different approach may be needed to teach self-management skills (i.e., being a good director of care, instead of a person who actually manages care independently). Furthermore, the most relevant and/or effective components of a self-management program in SCI are unknown. For example, content related to depression may be essential to a tailored self-management program in SCI given that it is associated with poorer outcomes, including increased secondary medical conditions and decreased self-care dependency (Elliot & Frank, 1996; Elliot & Kennedy, 2004).

These findings, together with the fact that the CDSMP has been criticized for its small to moderate effect sizes with respect to health outcomes and health care utilization, its lack of detailed attention to the role of significant others (family members/caregiver-attendants) in the promotion of targeted self-management behaviours, the sustainability of these outcomes in the long term, and its lack of specificity for disease conditions (Foster et al., 2007) point to the need for a tailored self-management program for individuals with SCI.

1.1.8 Medical Research Council Framework for the Design and Evaluation of Complex Interventions

In order to develop a sustainable and relevant self-management program to specifically meet the needs of individuals with SCI in the prevention and management of secondary complications, this thesis is informed by the new Medical Research Council framework for the design and evaluation of complex interventions to improve health (Campbell et al., 2000; Craig et al., 2008). This framework suggests that it is useful to consider the process of development and evaluation of complex interventions as having several distinct phases (see Figure 1.2). Progression from one phase to another may not be linear, and in many cases, an iterative process occurs. For example, if an exploratory trial finds that a complex intervention is unacceptable to
potential recipients, the theoretical basis and components of the intervention may have to be re-examined. Preliminary work is often essential to establish the probable active components of the intervention so that they can be delivered effectively during the trial. This preliminary work is the focus of this thesis— the considerations for self-management support need to be understood and determined first so that a relevant and sustainable program can be developed and evaluated. There are four key elements of the new Medical Research Council framework including, development, feasibility and piloting, evaluation, and implementation. This thesis focuses on the development phase. In this phase, it is rationalized that before a substantial evaluation is undertaken, the intervention must be developed to the point where it can reasonably be expected to have a worthwhile effect. The researcher must identify what is already known about similar interventions and the methods that have been used to evaluate them. Kastner and Straus (2012) have previously outlined the integration of the Medical Research Council and the Knowledge to Action Frameworks to develop and test a knowledge translation intervention. Key processes of the Knowledge to Action framework will also be applied in the current research initiative.

Figure 1.2: The New Medical Research Council Framework for the Evaluation of Complex Interventions (Craig et al., 2008)
1.1.9 The Knowledge-to-Action Framework

The Knowledge-to-Action framework incorporates the common elements of more than 30 planned action theories and was developed by Graham and colleagues (2006). It has been adopted by the Canadian Institutes of Health Research (CIHR) as the accepted model for promoting the application of research and a framework for the process of knowledge translation.

In this model, the knowledge-to-action process is described as iterative, dynamic, and complex; specifically, the boundaries between the components of knowledge creation and the action cycle (i.e., knowledge application) are permeable. Furthermore, in the application of the model, the end users of the knowledge should be included in the entire process to ensure that the knowledge and its subsequent implementation are relevant to their needs (i.e., as is the case in the current research) (Straus et al., 2011).

1.1.9.1 Knowledge Creation

According to the Knowledge-to-Action framework, knowledge creation, or the production of knowledge, is composed of three phases: knowledge inquiry, knowledge synthesis, and creation of knowledge tools (Graham et al., 2006). As knowledge is funneled through each stage in the knowledge creation process, the resulting knowledge becomes more refined and potentially more useful to end users. At the tools development stage, the best quality knowledge and research is further distilled into decision-making tools (e.g., practice guidelines or patient decision aids) (Straus et al., 2011).

1.1.9.2 The Action Cycle

The seven action phases of the Knowledge-to-Action framework can occur sequentially or simultaneously and the knowledge phases can influence the action phases at any point in the cycle. The action parts of the cycle are based on planned action theories that focus on
deliberately engineering change in health care systems and groups (Graham et al., 2005; 2007). Included are the processes needed to implement knowledge in health care settings specifically, identifying the problem (i.e., identify, review, select knowledge), adapting knowledge to the local context, assessing the determinants of knowledge use (i.e., barriers and facilitators), and selecting, tailoring, and implementing interventions. The current research focuses on these processes of the action cycle. Other elements of the cycle include monitoring knowledge use, evaluating outcomes, and sustaining knowledge use (Straus et al., 2011).

Figure 1.3: Knowledge-to-Action Framework (Graham et al., 2006)
1.1.10 Transformative Paradigm

The transformative paradigm is characterized as placing central importance on the lives and experiences of marginalized groups, such as women, ethnic/racial minorities, members of the gay and lesbian communities, those individuals who are poor, and individuals with disabilities. This paradigm as well as pragmatism are associated with rejecting forced choices between positivism/postpostivism and constructivism with regards to methods, logic, and epistemology, and thus are used in mixed methods research. The transformative perspective embraces features associated with both points of view (i.e., positivism/postpostivism and constructivism). Thus, in the present research, the transformative paradigm is a useful perspective given that the population of interest is individuals with traumatic SCI. Using this perspective, asymmetric power relationships are analyzed, the results of social inquiry are linked to action, and the results of inquiry are linked to wider questions of social inequity and social justice (Mertens, 2003).

1.2 SUMMARY AND IMPLICATIONS

A SCI results in a number of impairments which predispose a person to multisystem dysfunction, leading to an increased likelihood of a range of secondary complications. As length of stay in rehabilitation has shortened, there is a resulting emphasis on the management of SCI and its related secondary complications in the community. At the same time, efforts to reduce secondary complications in SCI must involve not only increasing knowledge (education) of risk and protective factors for secondary complications, but also self-monitoring and social support, timely referral to professional health care, and skills to minimize risk. A self-management program would be one approach to addressing these complex needs.
Although the CDSMP is one of the most validated and widely used programs (Lorig et al., 1999; 2001), a recent qualitative study by Hirsche and colleagues (2011) on the experiences of individuals with neurological conditions, including stroke, MS, and SCI, who participated in the CDSMP, determined that the participants with SCI reported the least satisfaction with the program. Individuals with SCI as well as some of the program leaders themselves suggested assembling a SCI-focused group (e.g., individuals with SCI needed information specific to and modules adopted for being in a wheelchair/reduced mobility). In addition, they also found that when attendant care is an important component (as is the case in individuals with SCI), a different approach may be needed to teach self-management skills (i.e., being a good director of care, instead of a person who actually manages care independently) (Hirsche et al., 2011). In addition, content related to depression may be essential to a tailored self-management program in SCI given that it is associated with poorer outcomes, including increased secondary medical conditions and decreased self-care dependency (Elliot & Frank, 1996; Elliot & Kennedy, 2004).

These findings, together with the fact that the CDSMP has been criticized for its small to moderate effect sizes with respect to health outcomes and health care utilization, its lack of detailed attention to the role of significant others (family members/caregiver-attendants) in the promotion of targeted self-management behaviours, the sustainability of these outcomes in the long term (i.e., outcomes are typically only reported at 6-12 months post-intervention) and its lack of specificity for disease conditions (Foster et al., 2007) point to the need for a targeted self-management program for individuals with SCI.
1.3 OVERALL AND SPECIFIC RESEARCH OBJECTIVES

1.3.1 Overall Research Objective

Therefore, the overall objective of this thesis was to understand the phenomenon of self-management in individuals with traumatic SCI (i.e., facilitators and barriers of self-management as well as the meaning of self-management), and then based on this understanding, determine the specific implementations considerations (i.e., components) for a targeted self-management program for individuals with SCI. Given the design of the current thesis (to be described in Chapter 2), Objectives 3 and 4 were determined based on the results of Objectives 1 and 2. It is hypothesized that individuals with traumatic SCI will have unique needs related to self-management and these unique needs will be used to formulate a corresponding self-management program.

1.3.2 Specific Research Objectives

To accomplish this, the following specific research objectives were addressed, with each objective corresponding to Papers 1-4:

1. To understand the perceived facilitators and barriers to self-management to prevent secondary complications from the perspectives of individuals with traumatic SCI, their family members/caregivers, and managers from acute care/trauma and rehabilitation centres (Paper 1/Chapter 3);

2. To understand the meaning of self-management in traumatic SCI from the perspectives of individuals with traumatic SCI and their (mainly) spousal caregivers as well as acute care/trauma and rehabilitation managers (Paper 2/Chapter 4);

3. To determine the relevant components of a self-management program for individuals with traumatic SCI (Paper 3/Chapter 5); and,
4. To identify some of the psychological characteristics (i.e., self-efficacy, mastery, patient activation) in self-management that are associated with depression in individuals with a traumatic SCI (Paper 4/Chapter 6).
Chapter 2
Overview of the Study Design and Thesis

2.1 OVERVIEW OF STUDY DESIGN

This thesis used a mixed methods inquiry approach with an exploratory design. This is a two-phase sequential design, whereby the results of the first method (qualitative) can help to develop or inform the second method (quantitative) (Greene et al., 1989). Because this design begins qualitatively, it is best suited for exploring a phenomenon (Creswell et al., 2003). This design is particularly useful for the (future) development of an intervention, as is the case in the current thesis (i.e., the considerations revealed in this research could be used for the future piloting, evaluation, and implementation of a tailored self-management support program for individuals with traumatic SCI) (Kroll & Morris, 2009). That is, it is believed that this design can increase the relevance and feasibility of a future intervention (i.e., the implementation of this targeted program) by tailoring the intervention to the patient population, thereby increasing the likelihood for successful implementation and uptake (Kontos & Poland, 2009).

2.1.1 Phase I Approach and Objectives

Specifically, Phase I used semi-structured interviews to understand the perceived facilitators and barriers to self-management to prevent secondary complications, as well as the meaning of self-management for individuals with traumatic SCI from the perspectives of individuals with traumatic SCI, their (mainly) spousal caregivers, and managers from acute care/trauma and rehabilitation centres.
2.1.2 Phase II Approach and Objectives

For Phase II, and consistent with the sequential exploratory design, the results gleaned from Phase I were used to develop a survey on self-management in individuals with traumatic SCI and substantiate the findings from the large-scale survey by revisiting the results from Phase I. Specifically, the survey was based on the themes that emerged in the Phase I studies on the facilitators and barriers to self-management in traumatic SCI (i.e., influence of positive/negative mood, self-efficacy) and the meaning of self-management in this population as well as the relevant psychological elements (i.e., module on depression)/underlying theory of the CDSMP (i.e., social cognitive theory and self-efficacy). From this survey, the relevant components of a self-management program for individuals with traumatic SCI were determined to confirm the specific needs and preferences for a targeted self-management program from the perspective of individuals with traumatic SCI.

In addition, based on the results of both Phase I (specifically, objective 1) and Phase II (objective 3), it was evident that mood was both an important facilitator and barrier to self-management, and that despite a high proportion of participants having a high patient activation (i.e., self-management) score, a significant portion of this sample also had a depression score consistent with a clinically depressed mood. Thus, the fourth objective of this thesis explored this complexity and identified some of the psychological characteristics (i.e., self-efficacy, mastery, patient activation) in self-management that are associated with depression in individuals with a traumatic SCI.

2.2 OVERVIEW OF THESIS

The results of this thesis are presented in four distinct but connected papers (Chapter 3-6), as summarized below. The final chapter (Chapter 7) summarizes the four studies of the
thesis, synthesizes the two phases, discusses the strengths and limitations of this research, outlines suggestions for future research in self-management and SCI, and describes the clinical/policy implications of this thesis.

Chapter 3 (Paper 1).

Title: Perceived Facilitators and Barriers to Self-Management in Individuals with Traumatic Spinal Cord Injury: A Qualitative Descriptive Study

The purpose of this paper was to understand the phenomenon of self-management in individuals with traumatic SCI, specifically to have a greater understanding of the self-management strategies adopted by individuals with SCI and the potential need for a tailored self-management program. The objective of this study was to understand the perceived facilitators and barriers to self-management to prevent secondary complications from the perspectives of individuals with traumatic SCI, their family members/caregivers, and managers from acute care/trauma and rehabilitation centres.

Chapter 4 (Paper 2).

Title: Meaning of Self-Management from the Perspective of Individuals with Traumatic Spinal Cord Injury, their Caregivers, and Acute Care and Rehabilitation Managers: An Opportunity for Improved Care Delivery

Consistent with paper 1, the purpose of paper 2 was to further understand the phenomenon of self-management in individuals with traumatic SCI. The objective of this paper was to understand the meaning of self-management in traumatic SCI from the perspectives of individuals with traumatic SCI and their (mainly) spousal caregivers as well as acute care/trauma and rehabilitation managers.
Chapter 5 (Paper 3).

Title: Patient Perspectives on the Components of a Self-Management Program for Individuals with Traumatic Spinal Cord Injury: Results from a National Survey

The purpose of this paper was to determine the specific implementations considerations (i.e., components/modules, modes of delivery, format, etc.) for a targeted self-management program for individuals with SCI. The objective of this paper was to determine the relevant components of a self-management program for individuals with traumatic SCI.

Chapter 6 (Paper 4).

Title: Examining the Impact of Psychological Characteristics in Self-Management in Individuals with Traumatic Spinal Cord Injury: Results from a National Survey

The fourth objective of this thesis further explored the complexity that the results from both phases shed light on by identifying some of the psychological characteristics (i.e., self-efficacy, mastery, patient activation) in self-management that are associated with depression in individuals with a traumatic SCI.
Abstract

Background: Current evidence has suggested the need for increased self-management support efforts in spinal cord injury (SCI) to reduce secondary complications. However, current self-management programs may not be suitable for the unique needs of individuals with SCI, including reduced mobility and the importance of attendant care. There is a need for greater understanding of the self-management strategies adopted by individuals with SCI and the potential need for a tailored self-management program. Thus, the purpose of the current study was to understand the perceived facilitators and barriers to self-management to prevent secondary complications.

Methods: A descriptive qualitative approach was used and involved telephone interviews. Semi-structured interviews were conducted with individuals with traumatic SCI, their family members/caregivers, and managers from acute care/trauma and rehabilitation centres. Participants were recruited between September 2011 and May 2012. Analysis was conducted using inductive thematic analysis to understand the perceived facilitators and barriers to self-managing to prevent secondary complications.

Results: A total of 26 interviews were conducted and they included 7 individuals with traumatic SCI (5 individuals with paraplegia, 2 individuals with quadriplegia; time since injury (range): 2-25 years), 7 family/caregivers (i.e., 7 SCI-caregiver dyads), and 12 acute care/rehabilitation managers from across the province of Ontario. The following five facilitators to self-
management were identified: physical support from the caregiver, emotional support from the
caregiver, peer support and feedback, importance of positive outlook and acceptance, and
maintaining independence/control over care. The following five barriers to self-management
were identified: caregiver burnout, funding and funding policies, lack of accessibility, physical
limitations and secondary complications, and difficulties achieving positive outlook or mood.

Conclusions: The current study demonstrated that the caregiver, peer support, perceived control
and self-efficacy, mood, and accessibility and funding policies make significant contributions to
the self-management of individuals with traumatic SCI. The issues of timing/readiness and
comorbidities and aging were observed across many of these themes. As such, the development
of a tailored self-management program for individuals with traumatic SCI and their caregivers
should incorporate these considerations.
3.1 INTRODUCTION

3.1.1 Spinal Cord Injury and Secondary Complications and Health Care Utilization

A spinal cord injury (SCI) results in a number of motor, sensory, and autonomic impairments which predisposes a person to multisystem dysfunction, leading to an increased likelihood of a range of related secondary complications (Berkowitz, 1993; Savic et al., 2000; Cardenas et al., 2004; Paker et al., 2006), defined as medical consequences that can cause functional limitations (Noreau et al., 2000). A cross-sectional study from the US Model System determined that 95.6% of patients had at least one medical complication at the time of their routine annual check-up (Anson & Shepherd, 1996). Common secondary health complications after SCI include pressure ulcers, urinary tract infections, bowel problems, fractures, chronic pain, and depressive disorders (Noreau et al., 2000). Despite the fact that many of these complications are amenable to treatment and/or prevention, secondary complications represent a significant burden at both the health system and individual level: they are costly, in terms of limited health-care resources including direct and indirect costs (Dryden et al., 2005; Dorsett & Geraghty, 2008; Munce et al., 2013), and they intensify the experience of disability for people with SCI by negatively impacting on long-term health, productivity/employment, dignity, mobility, and independence (Post & Noreau, 2005).

As a result of secondary complications, individuals with SCI have greater rates of contact with the health care system than the general population, and also have multiple rehospitalizations throughout their lifetime. Jaglal and colleagues (2009) reported a one year readmission rate of 27.5% among individuals with traumatic SCI in Ontario. Secondary complications were the main reasons for readmission. In a related study, a high number of visits to family physicians and physiatrists were reported (Munce et al., 2009). The authors concluded that the high rate of
physician and specialist utilization, emergency department visits, and hospital readmissions, in and of themselves, indicate that current self-care practices are not managing or preventing secondary complications adequately and indicated that future research should examine preventive strategies that could be implemented in order to improve the long-term quality and cost of care for persons with traumatic SCI (Jaglal et al., 2009; Munce et al., 2009).

3.1.2 Need for Preventative Strategies in the Community

Current evidence has suggested the need for increased SCI self-management support efforts to reduce secondary complications, including good knowledge of risk and protective factors for secondary complications, skills to minimize risk, self-monitoring and social support, and timely referral to professional health care (Kroll et al., 2007). A study of care received, care needs and preventability of secondary complications among persons with long-term SCI living at home reported that there were substantial unmet needs (van Loo et al., 2010). Information, psychosocial care, and self-efficacy were areas that needed to be enhanced and the need to explore self-management strategies was recommended. Similarly, Pang and colleagues (2009) determined that confidence or self-efficacy to manage SCI in many community-living people with SCI is suboptimal.

3.1.3 Chronic Disease Self-management Program in Spinal Cord Injury

A qualitative study on the experiences of individuals with neurological conditions, including stroke, multiple sclerosis, and SCI, who participated in the Stanford Chronic Disease Self-Management Program (CDSMP), determined that the participants with SCI reported the least satisfaction with the program. Individuals with SCI as well as some of the facilitators themselves suggested assembling a SCI-focused group (e.g., individuals with SCI needed information specific to and modules adopted for being in a wheelchair/reduced mobility). In
addition, they also found that when attendant care is an important component (as is the case in individuals with SCI), a different approach may be needed to teach self-management skills (i.e., being a good director of care, instead of a person who actually manages care independently) (Hirsche et al., 2011). Collectively, these findings point to the need for greater understanding of the self-management strategies adopted by individuals with SCI who are managing well. This information could then be used to inform the components of a self-management program for individuals with SCI.

3.1.4 Research Objectives

The objective of the current study was to understand the perceived facilitators and barriers to self-management to prevent secondary complications from the perspectives of individuals with traumatic SCI, their family members/caregivers, and managers from acute care/trauma and rehabilitation centres. This is the first study to the best of our knowledge to understand the facilitators and barriers of self-management in SCI and from such multiple perspectives.

3.2 METHODS

3.2.1 Conceptual Framework

Key processes of the Knowledge-to-Action framework informed the current research initiative (Graham et al., 2006). This framework incorporates the common elements of more than 30 planned action theories and was developed by Graham and colleagues (2006). It has been adopted by the Canadian Institutes of Health Research (CIHR) as the accepted model for promoting the application of research and a framework for the process of knowledge translation. The current study focuses on the facilitators and barriers phase with the view to developing a
new self-management program based on the facilitators and barriers identified in the current study.

3.2.2 Design/Approach

The present study took a descriptive qualitative approach using telephone interviews. This approach was employed as there is a paucity of research on self-management in individuals with traumatic SCI as well as their caregivers and the qualitative descriptive approach is well-accepted for researching topics about which little is known and yielding practical answers of relevance to policy makers and health care practitioners (Sandelowski, 2000; 2010). Given the potentially important role that caregivers have in the self-management of individuals with SCI, as outlined above, individuals with traumatic SCI and their caregivers (“the SCI-caregiver dyad”) were included. Health care (or clinical) managers from adult acute care/trauma and rehabilitation centres were included in order to triangulate the findings from a health care professional and/or health system perspective. Given the geographic diversity as well as the potential accessibility limitations of the study participants, telephone interviews were conducted. Using this approach, it is assumed that the current findings could be used to develop a tailored self-management program for individuals with traumatic SCI. Research ethics approval was obtained from the University of Toronto (Protocol Reference #26429). All participants provided informed consent prior to the interview.

3.2.3 Recruitment

Community-based (i.e., non-hospital based) individuals with traumatic SCI were recruited via 1) an online advertisement posted on the SCI Canada-Ontario web site; 2) a print advertisement included in the SCI Canada-Ontario magazine “Outspoken”; 3) postings and direct personal interactions with Regional Services Coordinators from various SCI Canada-Ontario
branches; and, 4) a community exercise rehabilitation program at McMaster University in Hamilton, Ontario (“MacWheelers”). Purposive sampling was used to identify and subsequently recruit study participants (Patton, 2002). Some of the criteria for purposeful sampling included participants’ urban and rural status. Individuals with traumatic SCI who were interested in the study contacted the principal investigator (SM) by telephone or email to inquire about the study. Eligible participants included individuals who were 1) 18 years of age or older; 2) fluent in English; 3) had experienced a traumatic SCI (e.g., a fall, motor vehicle accident, sporting accident, etc); and, 4) who had a formal or informal caregiver who was willing to participate. Caregivers/family members were recruited via the individuals with traumatic SCI and were identified as the individual’s primary caregiver. Individuals with traumatic SCI and their family member/caregiver were interviewed separately to mitigate potential power imbalances, which would influence the experiences they would be willing to share. The contact information of managers from acute care/trauma and rehabilitation centres across Ontario that are recognized for treating individuals with SCI was identified via Internet searches. Managers were subsequently contacted by telephone, informed of the study, and asked whether or not they wished to be interviewed. Participants were recruited between September 2011 and May 2012. Recruitment ceased as the study approached the point of data saturation, which is the point when successive interviews become repetitive and no new responses or themes emerged (Creswell et al., 2003).

3.2.4 Data Collection

Each participant took part in a semi-structured telephone interview lasting approximately 60-75 minutes. The interviews were conducted by the principal investigator (SM). The interview guide consisted of semi-structured open-ended questions (see Table 3.1) and was pilot
tested with a scientist experienced in qualitative methods (FW) as well as an individual with a
SCI. Probes or recursive questioning were used during interviews to explore issues in greater
depth and verify the interviewer’s understanding of the information being collected (Creswell et
al., 2003). Slight variations existed in the interview guide depending on the participant group
(see Table 3.1). All interviews were digitally recorded and transcribed verbatim for data
analysis.

3.2.5 Data Analysis

To facilitate the organization and analysis of the qualitative data, reflective notes from the
interviews, as well as the transcripts were entered into NVivo 9 (QSR, Victoria, Australia).
Analysis was conducted using inductive thematic analysis as described by Braun and Clark
(2006) to understand the perceived facilitators and barriers to self-management in traumatic SCI.
Following verification of the accuracy of the transcripts by the interviewer, two researchers (SJ,
FW) other than the principal investigator read a sample of the transcripts to become familiar with
the data. The interview transcripts were initially coded manually by the principal investigator
(SM), giving full attention to all data. Following this, the codes were clustered into groups that
shared similar meanings. At this point, three of the researchers (SM, SJ, FW) met to discuss the
coding of a sample of the transcripts as well as the data assigned to the codes and themes. New
themes were also discussed. Together, the researchers explored various thematic maps until
consensus was reached and theme labels were agreed.

3.3 RESULTS

3.3.1 Description of Participants

A total of 26 interviews were conducted, which included 7 individuals with traumatic SCI
(5 individuals with paraplegia, 2 individuals with quadriplegia; time since injury (range): 2-25
years), and 7 family/caregivers (i.e., 7 dyads), and 12 acute care/rehabilitation managers from
across the province. Characteristics of the individuals with traumatic SCI are reported in Table
3.2. In terms of the family member/caregiver group, five were spouses (female), one was a
sibling (male), and one was a personal support worker (female). The age range of the family
members/caregivers was 39 to 65 years of age. All of the acute care/trauma and rehabilitation
managers were female with an age range of 36 to 62 years of age. The number of beds at the
centres that these managers represented ranged from 12 to 63. Overall, 7 of the 26 participants
lived in Northern Ontario. To protect anonymity, quotes exemplifying the various themes only
include the participant’s group (i.e., individuals with traumatic SCI, family member/caregiver,
manager) and his or her sex.

3.3.2 Facilitators to Self-Management

The following five facilitators to self-management were identified: physical caregiver
support, emotional caregiver support, peer support and feedback, importance of positive outlook
and acceptance, and maintaining independence/control over care. Representative quotes of the
facilitators to self-management have been compiled in Table 3.3.

3.3.2.1 Physical Support from the Caregiver

Participants across the three groups noted the significant role that caregivers played in
terms of providing physical support. Physical support was described by participants as
assistance with basic (e.g., bathing, dressing) and instrumental (e.g., housework, meal
preparation) activities of daily living as well as assistance with the prevention/monitoring and/or
management of secondary complications. It was noted that some of these supportive skills (e.g.,
bowel and bladder management, wound care) were taught to family members early in the course
of the patient’s rehabilitation stay and staff recognized the importance of family members in this
role. There was also recognition of aging caregivers and/or caregivers with one or more chronic condition(s) themselves. As a result, participants expressed concern about the sustainability of this support and even the potential absence of this support.

3.3.2.2 Emotional Support from the Caregiver

Similarly, the significant role of the caregiver in terms of providing emotional support to the individual with the traumatic SCI was recognized, particularly among the individuals with the traumatic SCI as well as their caregivers. This type of support often involved encouraging and advocating for the individual with SCI.

3.3.2.3 Peer Support and Feedback

Peer support and feedback was also described as an important facilitator to self-management. Most participants referenced the Peer Support Program provided by SCI Canada and highlighted its value in pairing a newly injured individual with an individual who is several years post-injury. During peer support interactions, it was noted that the newly injured individual could share his or her fears/frustrations and that the individual who was several years post-injury could share his or her own experiences and thus offer assurances and/or expectations in the recovery course. The timing of this support was noted by several participants (e.g., that the individual with the traumatic SCI may not be ready to receive the support and/or information) as well as the need for considering and even matching some of the characteristics of the two parties (e.g., age, sex, level of injury). Some participants noted matching is an existing practice of SCI Canada when possible.

3.3.2.4 Importance of Positive Outlook and Acceptance

In addition to the beneficial roles of both family members/caregivers and peers, as described above, the individual’s own positive outlook and acceptance was stressed across the
participant groups as being key to their effective self-management. Some participants described this positive outlook as a characteristic that existed before the injury, but at the same time, it was also recognized that an individual’s outlook could evolve over the course of recovery. Finally, the potential roles of working or volunteering were recognized as contributing factors to this positive outlook.

### 3.3.2.5 Maintaining Independence/Control over Care

Across all participant groups, the importance of the individual with SCI maintaining control over care also emerged as an important facilitator to self-management. In some instances, this independence was tied to increased mobility, and specifically, having access to a vehicle and being able to drive.

### 3.3.3 Barriers to Self-Management

The following five barriers to self-management were identified: caregiver burnout, funding and funding policies, lack of accessibility, physical limitations/secondary complications, and difficulties achieving positive outlook or mood. Representative quotes of the barriers to self-management have been compiled in Table 3.4. The facilitators and barriers have also been represented in Figure 3.1.

#### 3.3.3.1 Caregiver Burnout

Caregiver burnout was identified as a major barrier to self-management on the part of individuals with traumatic SCI and this was well-recognized across all participant groups. Given the role that family members/caregivers play in care processes and overall well-being of individuals with traumatic SCI, several participants believed that caregiver burnout could threaten the sustainability of these critical supports. Indeed, the dual role of family members – most often wives in the current study – as both a spouse and performing the duties of a nurse was
highlighted as a stressor. A lack of specialized or targeted services/programs for family members/caregivers to address this burden was also noted.

3.3.3.2 Funding and Funding Policies

Funding and funding policies that do not promote quality of life were also described across the participant groups as major barriers to self-management among individuals with traumatic SCI. In the absence of this funding and associated services and policies, family members are often required to fill these system-level gaps (e.g., provide attendant care in the absence of/as a result of decreased funding for homecare providers). Differences in the funding of services or different levels of service based solely on the mechanism of injury were also outlined.

3.3.3.3 Lack of Accessibility

Accessibility was highlighted as another barrier to self-management across all of the participant groups. It was often discussed in terms of accessing buildings, and more specifically, difficulties with accessing physician offices and/or exam tables. One rehabilitation manager even suggested that as a result of these specific difficulties, individuals with SCI must access the emergency department to receive care.

3.3.3.4 Physical Limitations and Secondary Complications

Physical limitations of the injury and secondary complications in and of themselves were recognized as barriers to self-management among individuals with traumatic SCI. These limitations may affect the ability to live well with a SCI and/or even the ability to carry out activities of daily living.
3.3.3.5 Difficulties Achieving Positive Outlook or Mood

Finally, a negative outlook or mood and/or lack of self-advocacy were identified as barriers to self-management, mirroring the identification of a positive outlook and acceptance as a facilitator to self-management. The impact of a concurrent traumatic brain injury was also described as a potential contributing factor to this negative outlook or mood or lack of self-advocacy, with some participants describing observable changes to personality and/or motivation/perseverance.

3.4 DISCUSSION

The current study aimed to understand the facilitators and barriers to self-management and, to the best of knowledge, is the first study to amalgamate the perspectives of individuals with traumatic SCI, their family members/caregivers, and acute care and rehabilitation managers on self-management in SCI. Using a descriptive qualitative approach, the five major facilitators were identified as: physical caregiver support, emotional caregiver support, peer support and feedback, positive outlook and acceptance, and maintaining independence/control over care. Conversely, the five major barriers were: caregiver burnout, funding and funding policies, accessibility, physical limitations and secondary complications, and negative outlook or mood or lack of self-advocacy. Collectively, and consistent with the Knowledge-to-Action framework (Graham et al., 2006) that guided the current study, these identified facilitators and barriers could inform implementation considerations for self-management programs for individuals with traumatic SCI and their caregivers (see Table 3.5 for Summary).

3.4.1 Role of Caregivers

Collectively, this study demonstrated that caregivers, in this case, mainly wives of individuals with traumatic SCI, are making significant contributions to the physical and
emotional well-being of individuals with traumatic SCI (i.e., their self-management). Indeed, it is well-recognized that the caregivers of individuals with SCI often become the primary source of help for a wide range of activities including bathing, dressing, and feeding the individual with SCI as well as providing bowel and bladder care (Shewchuk et al., 1998), and as such, assume an “unexpected career” (Aneshensel et al., 1995). Despite the complexity of some of these tasks, it has been previously reported that caregivers of individuals with SCI may enter this new role without preparation or specialized training (Elliott & Rivera, 2003; Dickson et al., 2010). While many of the caregiver and manager participants acknowledged some skills training for caregivers at the rehabilitation phase of recovery, the need for ongoing training that is responsive to the evolving needs of individuals with traumatic SCI should be considered.

Furthermore, in performing these activities, the dual role of caregivers – as both a spouse and performing the duties of a nurse was highlighted as an important stressor. Dickson and colleagues (2010) identified a related theme of “post-injury shift in relationship dynamics” (i.e., re-definition of the partner role) in their study on the impact of assuming the primary caregiver role following traumatic SCI. This identified change in relationship dynamics was associated with a loss of identity in the caregiver (i.e., either a complete loss of identity or the emergence of a new “caregiver” identity), highlighting the extent of the caregiver role in SCI, as does the current study. This role change from husband or wife to caregiver has also been found in stroke caregivers (Hunt & Smith, 2004). However, unlike stroke, the functionality of the individual with SCI does not improve over time, and thus, the activities/level of support of caregivers of individuals with SCI may not diminish over time (Dickson et al., 2010).

While previous studies have emphasized the (physical) tasks associated with caregiving in SCI (e.g., Shewchuk et al., 1998; Dickson et al., 2010), the current study also highlighted the
significant emotional support that caregivers provide. This emotional support may contribute directly to increased self-management to reduce secondary complications among individuals with traumatic SCI or act as an important contributor in a path of actions/behaviours that lead to increased self-management (e.g., the emotional support provided by the caregiver increases the self-efficacy of the individual with traumatic SCI which is in turn associated with increased self-management of secondary complications).

These physical and emotional contributions on the part of the caregivers of individuals with traumatic SCI are associated with a high level of caregiver burden, as identified in the current study and previous research. Indeed, elevated levels of physical stress, emotional stress, burnout, fatigue, anger and resentment, and depression among caregivers of individuals with SCI have been consistently reported (Weitzenkamp et al., 1997; Elliott & Shewchuk, 1998; Shewchuk et al., 1998; Elliott et al., 2001; Lucke et al., 2004; Dreer et al., 2007; Guilcher et al., 2013). Given the critical role of caregivers in self-management support of individuals with traumatic SCI, as well as the accompanying caregiver burden, interventions that address the ongoing needs of caregivers, including further skills training (e.g., as the individual with the traumatic SCI ages and has unique challenges brought about by the combined effects of aging and injury (Schulz et al., 2009)) and psychological support are necessary. Two recent studies of interventions to assist family caregivers have demonstrated promise in reducing the impact of this burden (Elliott & Berry, 2009; Schulz et al., 2009), and in doing so, may promote ongoing care and/or sustainability of the care provided to individuals with traumatic SCI. Participants in these studies also raised the issue of aging and/or chronic health conditions among caregivers as a threat to the sustainability of caregiving activities, especially given the extent of support required in SCI.
3.4.2 Role of Peer Support

Peer support also emerged as a significant facilitator to self-management among individuals with traumatic SCI. Learning from peers has been described as vital in the context of rehabilitation (Standal & Jesperson, 2008) and peer support, along with social support in general, has been shown to be a key factor in the adjustments for living with a SCI (Boschen et al., 2003). Haas and colleagues (2013) determined that the main benefits of a community peer support service for individuals with SCI were the psychological and emotional support by a person with a SCI, advice on living with a SCI, practical advice and information, and ongoing support and friendship. These findings are consistent with those of the current study as well as the findings of other studies in SCI, which have reported the value of non-specific psychological and emotional support through the input of a peer mentor (Boschen et al., 2003; Veith et al., 2006). Furthermore, previous research has determined that practical advice provided by a peer mentor has the potential to add to the knowledge base of individuals with SCI, increase their self-efficacy, thereby increasing the likelihood of adherence to self-management behaviours to prevent secondary medical conditions (Ljunberg et al., 2011). The importance of matching peer mentors and mentees by specific demographic and clinical/injury characteristics was identified in the current study. The importance of this matching has been recognized in previous studies whereby demographic/clinical information such as age, race, and etiology of injury was considered when assigning a potential mentee to a mentor (Ljunberg et al., 2011). Lastly, the issue of appropriate timing for mentorship activities was raised, with some SCI participants recognizing that the acute phase of recovery may be too early to receive support.
3.4.3 Role of (Perceived) Control and Self-Efficacy

Across all participant groups, the theme of maintaining control over care also emerged as a facilitator to self-management. Indeed, having a sense of control has consistently been found to have adaptive effects. In general, perceived control is associated with emotional well-being, reduced physiological impact of stressors, enhanced ability to cope with stress, improved performance, reduced pain, and a greater likelihood of making difficult behaviour changes (Thompson & Spacapan, 1991). Self-efficacy, defined as an individual’s belief or confidence in his or her capabilities to successfully execute the necessary courses of action to satisfy situational demands in the future, including those that are novel and stressful, is a construct of perceived control (Lorig et al., 1999; 2001). Decreased self-efficacy has been identified as a major factor to the lack of adherence with health and disease self-management (Taal et al., 1993), and thus it is not surprising that perceived control emerged as a facilitator to self-management in the current study. For example, it has been demonstrated that individuals with SCI who have higher self-efficacy demonstrate better mental health (Kennedy et al., 2012) and fewer secondary complications (Suzuki et al., 2007). Pang and colleagues (2009) demonstrated that those individuals with increased time since injury have better self-efficacy, but the results did not reach statistical significance. They concluded that it may take time for the newly injured individual to accept his or her own disabilities and learn to cope with the consequences of the condition and/or develop a better sense of control.

3.4.4 Role of Mood

The impact of mood was identified as both a facilitator and barrier to self-management in the current study. Indeed, others have found that the risk for major depression as well as anxiety disorder, post-traumatic stress disorder, substance abuse, and suicide is elevated for individuals
with SCI compared with the general population (DeVivo et al., 1991; North, 1999; Kennedy & Rogers, 2000; Galvin & Godfrey, 2001; Beedie et al., 2002; Craig et al., 2009). It has been suggested that activating inherent psychological resources including skills, knowledge, experiences, and behavioural patterns, may protect individuals with SCI from the negative secondary consequences of the injury (Peter et al., 2012), supporting the current study’s findings. It has been previously concluded that depression can “lead to apathy in terms of self-care” (Krause et al., 2001). However, studies also support the idea of “feedback loops” where certain patient factors and increased complications following depression may in turn accentuate the initial depression. Indeed, secondary complications were identified as a barrier to self-management in the current study and thus may be acting as barriers in and of themselves (i.e., decreases in functional capacity) or may be contributing to this described feedback loop. The impact of traumatic brain injury (i.e., associated with the initial injury) on the mood and/or the ability to self-advocate, as well as the impact of other co-morbid conditions, such as diabetes and heart disease, in SCI and/or secondary conditions was raised. As was identified in the discussions around peer support and self-efficacy in the current study, it was acknowledged that the role of mood/self-advocacy on self-management behaviour is not static and may evolve as the length of time since injury increases.

3.4.5 Role of Accessibility and Funding Policies

Limited accessibility to services and/or equipment, and in some cases, an associated lack of funding or funding policies that did not support accessibility were identified as barriers to self-management. In support of this finding, Lund and colleagues (2007) determined that individuals with SCI who perceive no serious barriers to participation in their daily lives report levels of life satisfaction that are similar to a healthy population. This suggests that perceptions of diminished
quality of life following SCI might be a consequence of environmental barriers and inequity of opportunity rather than the SCI itself (i.e., impairment, secondary conditions) or the individual’s own personal characteristics (Hammell, 2004; 2010). Moreover, the negative impact of limited mobility, societal barriers, inadequate/inaccessible services and uninformed policies on the development of preventable complications has only been recently recognized, suggesting that inequitable community access may contribute to perceptions of poor quality of life and secondary conditions, and that these consequences are inter-related. Thus, while improvement of the individual-level factors discussed above (i.e., self-efficacy, mood) may lead to increased self-management of secondary complications, the current findings suggest that health system-level factors (e.g., access and availability of services, models of care) also need to be improved in order to create the optimal conditions for self-management among individuals with traumatic SCI (Guilcher et al., 2013).

3.4.6 Limitations

The current study acknowledges some limitations. In terms of the recruitment procedure, it is likely that a selection bias operated in those participants who agreed to take part in the research – they may have been healthier and/or had better/more interest in self-management skills than those individuals who chose not to participate. Additionally, all participants had to have a caregiver who was willing to participate. At the same time, a certain level of intrinsic motivation and support is required in order to successfully participate in a self-management program (Bandura, 2004; Kehn & Kroll, 2009; Kooijmans et al., 2013), and thus it could be argued that the appropriate input was obtained for the development of a self-management intervention for individuals with traumatic SCI and their caregivers. The majority of traumatic SCI participants in the current study were male, which is consistent with the epidemiology of
population-based studies (e.g., Couris et al., 2010), with female caregivers. However, future research should attempt to focus on the perspective of females with a traumatic SCI as well as the perspectives of male caregivers in order to increase the applicability of the study findings.

3.4.7 Future Research

Further research is required in the area of interventions to promote caregiver well-being especially given caregivers’ critical role to the individual with traumatic SCI and the health care system as a whole. While previous research has focused on the area of physical support or activities of daily living, further research is required on the emotional support that caregivers provide to individuals with traumatic SCI and the associated patient outcomes. The issue of aging and/or chronic health conditions among caregivers as a threat to the sustainability of caregiving activities was also raised, especially given the extent of support required in SCI. Future research/interventions should address this important consideration. There is a need to further examine the mechanisms of the relationships and inter-relationships between mood (i.e., depression), self-efficacy, self-management adherence, and secondary complications in SCI. Future research could also determine a more comprehensive list of mentor/mentee characteristics and what specific characteristics or combination of characteristics are tied with increased self-management among individuals with traumatic SCI. Across several of the themes (peer support, perceived control and self-efficacy, mood), the issue of timing/readiness was raised. Again, future research should determine the appropriate levels of mentorship/support at varying stages of recovery in order to optimize moderating/mediating variables or outcomes of self-management (e.g., increased self-efficacy, decreased number of secondary conditions). The role of aging and comorbidity in SCI, in general, and as they relate to the identified themes warrants further research. Finally, current self-management programs (e.g., Lorig et al., 1999; 2001) lack
these components/considerations (e.g., emotional support for caregivers, issue of timing/readiness), and thus their relevance to generic and/or disease-specific programs could also be investigated for program development.

3.4.8 Conclusions

The current study is, to the best of our knowledge, the only study on the facilitators and barriers to self-management in traumatic SCI, which captures the perspectives of the individual with traumatic SCI, their caregivers, and health care professionals. Overall, the current study demonstrated that the caregiver, peer support, perceived control and self-efficacy, mood, and accessibility and funding policies make significant contributions to the self-management of individuals with traumatic SCI. The issues of timing/readiness and comorbidities and aging were observed across many of these themes. As such, the development of a tailored self-management program for individuals with traumatic SCI and their caregivers should incorporate these considerations (i.e., see Table 3.5). It is anticipated that such a program could have a dramatic impact on reducing secondary complications, attenuating caregiver burnout, and enhancing quality of life for individuals with SCI.
Table 3.1: Interview Guide for Facilitators and Barriers to Self-Management (including question variation examples by participant group)

<table>
<thead>
<tr>
<th>Examples of Open-Ended Questions from Interview Guide:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a. What are some of the factors that have contributed to success in self-management?</td>
</tr>
<tr>
<td>1b. Manager version: What do you believe are the facilitators to self-management for patients in the community at the individual, provider, and/or policy levels?</td>
</tr>
<tr>
<td>2a. What are some of the factors that have impeded success in/ability to maintain self-management?</td>
</tr>
<tr>
<td>2b. Manager version: What do you believe are the barriers to self-management for patients in the community at the individual, provider, and/or policy levels?</td>
</tr>
<tr>
<td>2c. Manager version: What could be added to your program to assist patients with self-management support/skills? What are the facilitators, barriers to making this/these addition(s) at the individual, provider, and/or policy levels?</td>
</tr>
<tr>
<td>3. What are you currently doing to prevent any secondary complications, that is, any medical conditions that arise as a result of your spinal cord injury, such as urinary tract infections or pressure ulcers?</td>
</tr>
<tr>
<td>4. What prompted your last visit to hospital or your physician’s office? What kind of specific help did you need after that visit (attendant care, etc.)? Who or what helped you meet these needs? Was there anything that was not helpful?</td>
</tr>
<tr>
<td>Example of Probes: How so? Tell me more about that.</td>
</tr>
</tbody>
</table>
Table 3.2: Characteristics of Individuals with Traumatic SCI

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N=7; n, Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
</tr>
<tr>
<td>Female</td>
<td>1</td>
</tr>
<tr>
<td>Age</td>
<td>39-68</td>
</tr>
<tr>
<td>Time since injury (years)</td>
<td>2-25</td>
</tr>
<tr>
<td>Level of injury</td>
<td></td>
</tr>
<tr>
<td>Paraplegia</td>
<td>5</td>
</tr>
<tr>
<td>Quadriplegia</td>
<td>2</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>&lt;High School</td>
<td>2</td>
</tr>
<tr>
<td>Undergraduate/college</td>
<td>4</td>
</tr>
<tr>
<td>Post-graduate</td>
<td>1</td>
</tr>
<tr>
<td>Employment Status</td>
<td></td>
</tr>
<tr>
<td>Unemployed/retired</td>
<td>5</td>
</tr>
<tr>
<td>Part-time</td>
<td>1</td>
</tr>
<tr>
<td>Full-time</td>
<td>1</td>
</tr>
<tr>
<td>Theme: Physical Support from the Caregiver</td>
<td>Source</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>“I do all the cooking, the cleaning. I was doing snow removal but then I gave it up. I do the grass cutting. I mean if there are light bulbs to be changed, just general maintenance around the house, anything that he can’t manage and the grocery shopping and the bill paying”</td>
<td>Caregiver 6; Wife of individual with traumatic SCI</td>
</tr>
<tr>
<td>“I mean some people will never be able to self-catheterize. So we educate their partner in care as to how they can help to do that. So they need to be taught at the same time as the individual patient. They need to know the risks in particular with you know I’m thinking of bladder dystonia and pressure sores, transferring and all of that. I mean these people aren’t going home to live by themselves. That’s quite rare. So they need to have the support service from their partner in care and family members and they need as much education as the patient does, sometimes more”</td>
<td>Manager 4; Female Rehabilitation Manager</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme: Emotional Support from the Caregiver</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>“When I’m confronted with situations like that, I kind of sort of buckle and break down. Thank God I have a husband who’s like a really strong advocate because I’d say he’s really more of the advocate than I am and when things go bad, he’s the one that can step in and advocate on my behalf to make sure that I get what I need”</td>
<td>TSCI 1; Female with traumatic SCI</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme: Peer Support and Feedback</th>
<th>Source</th>
</tr>
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<tbody>
<tr>
<td>“Often times when the patient is here or even when they’re in acute care, the CPA will hook up…and begin that dialogue about getting back into the community. While they’re inpatients here they also have what they call peer support workers. So they will buddy someone who’s had a former injury with a patient here who might have the same level of injury, be close in age. I think those are a couple of excellent facilitators for patients”</td>
<td>Manager 11; Female Rehabilitation Manager</td>
</tr>
</tbody>
</table>
Table 3.3: Themes and Representative Quotes of Facilitators to Self-Management (Continued)

<table>
<thead>
<tr>
<th>Theme: Positive Outlook and Acceptance</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘‘I accept the fact that…it was very difficult but I finally did accept the fact that I’m a quadriplegic and I’m going to be like this for the rest of my life. So I may as well just accept it and get on with it’’</td>
<td>TSCI 2; Male with traumatic SCI</td>
</tr>
<tr>
<td>‘‘With J., he has had jobs where he’s working, he has to get up…so he has to be at certain things. So he has to get out of bed. He has things to do. I could definitely… that would be something with other people in a wheelchair, there wouldn’t be any motivation and that affects everything; self-esteem, social skills. Then of course it affects their health because they’re not moving, they’re not doing things. They don’t have to be somewhere’’</td>
<td>Caregiver 4; Wife of individual with traumatic SCI</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme: Maintaining Independence/Control over Care</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘‘Well the idea of…for instance I knew that I needed some sort of satisfaction happy environment. So I decided right away to go back to drive a car. I remember I became very eager at that and I said that’s it, I could have a car’’</td>
<td>TSCI 7; Male with traumatic SCI</td>
</tr>
</tbody>
</table>
Table 3.4: Themes and Representative Quotes of Barriers to Self-Management

<table>
<thead>
<tr>
<th>Theme: Caregiver Burnout</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>“My concern is you get people who, especially if it’s a husband and wife thing where they don’t have the insurance and the husband has gotten to the point where I don’t want to do this anymore for myself and then the wife has to do it. That changes the dynamics too much. It has to happen regularly. How can you… I don’t know. How can you provide a hug and a kiss to somebody where you’ve just done their bowel care? It’s just too hard you know?”</td>
<td>Manager 2; Female Rehabilitation Manager</td>
</tr>
<tr>
<td>“So in pediatrics they have a family support service. Here [in the adult rehabilitation system] there’s not that same support. I’ve never even heard of a family support service. That helps them to understand even emotionally where they’re at so that are they able to be dealing with this...”</td>
<td>Manager 12; Female Rehabilitation Manager</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme: Funding and Funding Policies</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>“You know before we had a whole bunch of cuts happen, we used to have OTs [occupational therapists] go around. They would do certain rounds in the morning with the patients, the ones who have modified hand function. They would go around and take a look at and be there with the patient while they’re getting dressed and give the patient tips and see if they need adaptive devices that help them to put their socks on and get dressed and put their shoes on and also brushing their teeth”</td>
<td>Manager 2; Female Rehabilitation Manager</td>
</tr>
<tr>
<td>“Yes, it’s only auto insurance that provides case management. If you had a spinal cord injury at home, let’s say you fell off your roof while putting up Christmas lights, then you would be under one of the long-term disability or extended health providers and they don’t provide case management. WSIB [Workplace Safety and Insurance Board] doesn’t provide that either. They would probably say that they case manage their own file but it’s very much in an entitlement system. It’s only the auto files that actually will purchase objective third party case managers but only for catastrophically impaired”</td>
<td>Manager 8; Female Rehabilitation Manager</td>
</tr>
</tbody>
</table>
Table 3.4: Themes and Representative Quotes of Barriers to Self-Management (Continued)

<table>
<thead>
<tr>
<th>Theme: Accessibility</th>
<th>Representative Quote</th>
<th>Source</th>
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<tbody>
<tr>
<td></td>
<td>&quot;I know that there was a question of being able to... he always calls ahead kind of thing. If he knows certain exam rooms aren’t accessible, then we’ll try to request another one that’s easier for him to transfer. He definitely is aware of accessibility where he’s going to meet the doctors. I’m not sure if sometimes he might have to cram into a small room which is kind of ridiculous&quot;</td>
<td>Caregiver 4; Wife of individual with traumatic SCI</td>
</tr>
<tr>
<td>Theme: Physical Limitations and Secondary Complications</td>
<td></td>
<td>Caregiver 1; Personal support worker of individual with traumatic SCI</td>
</tr>
<tr>
<td></td>
<td>&quot;I think she is frustrated. Let’s say she wants to do something and she cannot do it, let’s say opening the jar and she cannot open it because her hand is not that strong to open a jar. Then if she wants to get something, even though she has this picker, a device she uses in getting something... If she wants to do something, she uses that picker and then she’s having a hard time, that frustrates her. But there are only a few things that I know frustrates her, like putting the clothes on the hanger and then the jar opening. Those are the two things that I find are being frustrated&quot;</td>
<td>Source</td>
</tr>
<tr>
<td>Theme: Negative Outlook or Mood</td>
<td></td>
<td>Caregiver 2; Wife of individual with traumatic SCI</td>
</tr>
<tr>
<td></td>
<td>&quot;Then also that other thing I said where he doesn’t feel he deserves that stuff, he won’t advocate for himself because he’s just a guy in a wheelchair and he’s useless anyway right. That’s not a healthy attitude but I would say that that maybe something that comes up with other people where you know they may not advocate for themselves because they don’t think they’re worth it. It’s sad really&quot;</td>
<td>Source</td>
</tr>
</tbody>
</table>
Table 3.5: Summary of Identified Facilitators and Barriers to Self-Management, Corresponding Self-Management Program Components, and Implementation Considerations in Individuals with Traumatic Spinal Cord Injury and their Caregivers

<table>
<thead>
<tr>
<th>Identified Facilitators (F), Barriers (B)</th>
<th>Suggested Self-Management Program Components/Modules</th>
<th>Implementation Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>-Physical support from the caregiver (F)</td>
<td>-Caregiver component (i.e., skills training and emotional support)</td>
<td>-Training and support for caregivers needs to be responsive to the evolving needs of individuals with traumatic SCI (i.e., as they age and/or develop chronic conditions) -The sustainability of caregiver activities and support required in SCI may be affected by aging and/or the chronic health conditions among caregivers themselves</td>
</tr>
<tr>
<td>-Emotional support from the caregiver (F)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-Caregiver burnout (B)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-Peer support and feedback (F)</td>
<td>-Peer support component</td>
<td>-Matching peer mentors and mentees by specific demographic and clinical/injury characteristics (age, sex, etiology of injury) should be considered -Timing of support should be considered (e.g., acute phase of recovery may be too early)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-Maintaining Independence/Control over Care (F)</td>
<td>-Self-efficacy component</td>
<td>-Time since injury may play an important role in (increasing) self-efficacy in traumatic SCI</td>
</tr>
<tr>
<td>-Importance of Positive Outlook and Acceptance (F)</td>
<td>-Mood (depression) component (or Mind-Body component)</td>
<td>-Time since injury may play an important role in (increasing) mood in traumatic SCI -Physical limitations and secondary complications, chronic conditions, and co-morbid traumatic brain injury should be considered</td>
</tr>
<tr>
<td>-Difficulty Achieving Positive Outlook or Mood (B)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-Physical Limitations and Secondary Complications (B)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-Funding and Funding Policies (B)</td>
<td>-Awareness/knowledge of various funding programs -Advocacy skills training</td>
<td>-Health system factors (funding, accessibility) need to be optimized for overall self-management optimization among individuals with traumatic SCI and their caregivers</td>
</tr>
<tr>
<td>-Lack of accessibility (B)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Facilitators to Self-Management:
- Physical support from the caregiver
- Emotional support from the caregiver
- Peer support and feedback
- Importance of positive outlook and acceptance
- Maintaining independence/control over care

Barriers to Self-Management:
- Caregiver burnout
- Funding and funding policies
- Lack of accessibility
- Physical limitations and secondary complications
- Difficulties achieving positive outlook or mood

Figure 3.1: Perceived Facilitators and Barriers to Self-Management across Individuals with Traumatic Spinal Cord Injury, their Family Members/Caregivers, and Acute Care/Trauma and Rehabilitation Managers
Chapter 4

Paper 2: Meaning of Self-Management from the Perspective of Individuals with Traumatic Spinal Cord Injury, their Caregivers, and Acute Care and Rehabilitation Managers: An Opportunity for Improved Care Delivery

[Submitted to Disability and Rehabilitation]

Abstract

Purpose: The objective of this study was to understand the meaning of self-management in traumatic spinal cord injury (SCI) from the perspectives of individuals with traumatic SCI and their (mainly) spousal caregivers as well as acute care/trauma and rehabilitation managers.

Method: A descriptive qualitative approach was used. Semi-structured interviews were conducted with 26 individuals with traumatic SCI, their family members/caregivers, and managers from acute care/trauma and rehabilitation centres.

Results: The meaning of self-management in SCI related to two overarching themes of internal responsibility attribution and external responsibility and revealed differences between the meaning of self-management in SCI among individuals with traumatic SCI and their caregivers versus acute care/trauma and rehabilitation managers. Overall, the meaning of self-management among the SCI and caregiver participants related principally to internal responsibility attribution. For the manager participants, the meaning of self-management was much narrower and the overarching theme of internal responsibility attribution that was observed among the SCI-caregiver dyads was not as widely expressed by this group.

Conclusions: The understanding of self-management from these varying perspectives could be applied to the development of a tailored and meaningful self-management program for individuals with traumatic SCI and their caregivers.
4.1 INTRODUCTION

The trend of decreasing length of stay in rehabilitation facilities has led to individuals with spinal cord injury (SCI) entering the community with unmet needs and fewer self-care skills to prevent secondary complications (Chen et al., 1999; McColl et al., 2012). Families and others comprising the informal support network for these people also have less time to adjust. As a result, there is some evidence to suggest that these reduced lengths of stay in rehabilitation, and ensuing consequences, lead to higher rates of secondary complications and subsequent high rehospitalization rates (Jones & Evans, 1998; Jaglal et al., 2009; Munce et al., 2009). Given this increasing emphasis on the community management of SCI, strategies that could be implemented in order to increase patients’ involvement and control of their medical treatment and its subsequent effects are required (Kroll et al., 2007). The implementation of a self-management program for individuals with SCI for the management of these complex needs, including secondary complications, may be one option to fill these care gaps, at least in part.

Self-management is commonly described as “…the individual’s ability to manage the symptoms, treatment, physical, and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses the ability to monitor one’s condition and to affect the cognitive, behavioural, and emotional responses necessary to maintain a satisfactory quality of life” (Barlow et al., 2001). Self-management has been reported as enabling individuals to minimize pain, share in decision making about treatment, gain a sense of control over their lives (Lorig & Holman, 1993; Barlow et al., 1999), reduce the frequency of visits to physicians, and enjoy a better quality of life (Lorig et al., 1998; Barlow et al., 2002). In SCI in particular, poor self-management has been identified as a significant factor in the
development of an inactive lifestyle, secondary conditions, and de-conditioning (Janssen et al., 1997; Warms et al., 2004).

Hirsche and colleagues (2011) recently conducted a qualitative study on the experiences of individuals with neurological conditions, including stroke, multiple sclerosis, as well as SCI, who participated in the Stanford Chronic Disease Self-Management Program (CDSMP). This study represented the first study to understand the experience of the CDSMP in individuals with SCI. Participants with SCI reported the least satisfaction with the CDSMP. Individuals with SCI as well as some of the leaders of this self-management group suggested assembling a SCI-focused group (e.g., individuals with SCI needed information specific to and modules adopted for being in a wheelchair/reduced mobility). In addition, they also found that when attendant care is an important component (as is the case in individuals with SCI), a different approach may be needed to teach self-management skills (i.e., being a good director of care, instead of a person who manages care independently) (Hirsche et al., 2011).

Much of the chronic illness self-management literature is from the perspective of health care professionals (e.g., Lorig et al., 1998; Barlow et al., 2000); thus, a greater understanding of the meaning of self-management (i.e., from varying perspectives) in specific populations is required in order to better tailor self-management support to the individuals and their caregivers. Thus, the objective of this study was to understand the meaning of self-management in traumatic SCI from the perspectives of individuals with traumatic SCI and their (mainly) spousal caregivers as well as acute care/trauma and rehabilitation managers. This is the first study, to the best of our knowledge, to understand the meaning of self-management in SCI from such multiple perspectives, and indeed one of only a few studies that includes a consumer perspective (i.e., patient and caregivers) on the meaning of self-management.
4.2 METHODS

4.2.1 Design/Approach

The present study took a descriptive qualitative approach using telephone interviews. This approach was employed as there is a paucity of research on self-management in individuals with traumatic SCI as well as their caregivers and the qualitative descriptive approach is well-accepted for researching topics about which little is known and yielding practical answers of relevance to policy makers and health care practitioners (Sandelowski, 2000; 2010). Given the potentially important role that caregivers have in the self-management of individuals with SCI, as outlined above, individuals with traumatic SCI and their caregivers (“the SCI-caregiver dyad”) were included. Health care (or clinical) managers from adult acute care/trauma and rehabilitation centres were included in order to triangulate the findings from a health care professional and/or health system perspective. Given the geographic diversity as well as the potential accessibility limitations of the study participants, telephone interviews were conducted. Using this approach, it is assumed that the current findings could be used to develop a tailored self-management program for individuals with traumatic SCI. Research ethics approval was obtained from the University of Toronto (Protocol Reference #26429). All participants provided informed consent prior to the interview.

4.2.2 Recruitment

Community-based (i.e., non-hospital based) individuals with traumatic SCI were recruited via 1) an online advertisement posted on the SCI Canada-Ontario web site; 2) a print advertisement included in the SCI Canada-Ontario magazine “Outspoken”; 3) postings and direct personal interactions with Regional Services Coordinators from various SCI Canada-Ontario branches; and, 4) a community exercise rehabilitation program at McMaster University in
Hamilton, Ontario (“MacWheelers”). Purposive sampling was used to identify and subsequently recruit study participants (Patton, 2002). Some of the criteria for purposeful sampling included participants’ urban and rural status. Individuals with traumatic SCI who were interested in the study contacted the principal investigator (SM) by telephone or email to inquire about the study. Eligible participants included individuals who were 1) 18 years of age or older; 2) fluent in English; 3) had experienced a traumatic SCI (e.g., a fall, motor vehicle accident, sporting accident, etc); and, 4) who had a formal or informal caregiver who was willing to participate. Caregivers/family members were recruited via the individuals with traumatic SCI and were identified as the individual’s primary caregiver. Individuals with traumatic SCI and their family member/caregiver were interviewed separately to mitigate potential power imbalances, which would influence the experiences they would be willing to share. The contact information of managers from acute care/trauma and rehabilitation centres across Ontario that are recognized for treating individuals with SCI was identified via Internet searches. Managers were subsequently contacted by telephone, informed of the study, and asked whether or not they wished to be interviewed. Participants were recruited between September 2011 and May 2012. Recruitment ceased as the study approached the point of data saturation, which is the point when successive interviews become repetitive and no new responses or themes emerged (Creswell et al., 2003).

4.2.3 Data Collection

Each participant took part in a semi-structured interview lasting approximately 60-75 minutes. The interviews were conducted by the principal investigator (SM). The interview guide consisted of semi-structured open-ended questions (see Table 4.1) and was pilot tested with a scientist experienced in qualitative methods (FW) as well as an individual with a SCI.
Probes or recursive questioning were used during interviews to explore issues in greater depth and verify the interviewer’s understanding of the information being collected (Creswell et al., 2003). Slight variations existed in the interview guide depending on the participant group (see Table 4.1). All interviews were digitally recorded and transcribed verbatim for data analysis.

4.2.4 Data Analysis

To facilitate the organization and analysis of the qualitative data, reflective notes from the interviews, as well as the transcripts were entered into NVivo 9 (QSR, Victoria, Australia). Analysis was conducted using inductive thematic analysis as described by Braun and Clark (2006) to understand the meaning of self-management in traumatic SCI. Following verification of the accuracy of the transcripts by the interviewer, two researchers (SJ, FW) other than the principal investigator read a sample of the transcripts to become familiar with the data. The interview transcripts were initially coded manually by the principal investigator (SM), giving full attention to all data. Following this, the codes were clustered into groups that shared similar meanings. At this point, three of the researchers (SM, SJ, FW) met to discuss the coding of a sample of the transcripts as well as the data assigned to the codes and themes/sub-themes. New themes and sub-themes were also discussed. Together, the researchers explored various thematic maps until consensus was reached.

4.3 RESULTS

4.3.1 Description of Participants

A total of 26 interviews were conducted, which included 7 individuals with traumatic SCI (5 individuals with paraplegia, 2 individuals with quadriplegia; time since injury (range): 2-25 years) and 7 family/caregivers (i.e., 7 dyads), and 12 acute care/rehabilitation managers from across the province. Characteristics of the individuals with traumatic SCI are reported in Table
4.2. In terms of the family member/caregiver group, five were spouses (female), one was a sibling (male), and one was a personal support worker (female). The age range of the family members/caregivers was 39 to 65 years of age. All of the acute care/trauma and rehabilitation managers were female with an age range of 36 to 62 years of age. The number of beds at the centres that these managers represented ranged from 12 to 63. Overall, 7 of the 26 participants lived in Northern Ontario. To protect anonymity, quotes exemplifying the various themes only include the participant’s group (i.e., individuals with traumatic SCI, family member/caregiver, manager) and his or her sex.

4.3.2 Overview of Themes

In the current study, the meaning of self-management related to two overarching themes of internal responsibility attribution and external responsibility attribution (Figure 4.1). Specifically, the sub-themes of wellness awareness, monitoring for secondary complications, independence-dependence conflict, self-management as an unknown term, directing someone else to provide your care, and ownership of your own care/empowerment in managing your own care comprised internal responsibility attribution. The sub-themes of established chronic disease self-management programs and the importance of caregiver skill set comprised external responsibility attribution. Responsibility attribution implies underlying and perhaps unexplored assumptions about who has responsibility and who assumes responsibility for self-management and health status. Responsibility is defined as taking on obligations to act in order to attain desired outcomes (Audulv et al., 2010). It is suggested that responsibility for disease management is attributed to different sources: some individuals assume responsibility (internal responsibility attribution) while others refer it to third parties such as employers, health care providers, or family members (external responsibility attribution) (Olsson et al., 2006; Larsson et
al., 2009). Furthermore, a clear delineation in the meaning of self-management was noted in the traumatic SCI and caregiver participants (i.e., the SCI-caregiver dyad) versus the manager participants (Figure 4.2).

4.3.3 Internal Responsibility Attribution

4.3.3.1 Wellness Awareness

Wellness awareness included lifestyle practices/changes including good nutrition, vitamin supplementation, exercise, and relaxation that these participants associated with living well and maintaining/optimizing health. This sub-theme is encapsulated by the following quotes:

“Physical fitness, healthy eating, paying attention to what’s going on with the skincare, keeping your brain active, keep everything going, don’t spend too much time in front of the TV” (SCI 6; Male with traumatic SCI).

“Both of us have decided the best way is to exercise. So we’re exercising more, going on longer walks, trying to take walks instead of drive in cars short distances and that kind of thing, try to eat more healthy. I don’t know if he told you but both of us have been eating very healthy the last year and a half. I became a vegetarian about a year and a half and he’s about 85%, 90% vegetarian. We’re just more health-wise, that kind of thing” (Caregiver 4; Wife of individual with traumatic SCI).

4.3.3.2 Monitoring for Secondary Complications

Participants described monitoring for secondary complications or being proactive about preventing secondary complications as a component of self-management in SCI. This monitoring or proactive behavior was often associated with a specific routine:
“Then routines to my day, the washing up rituals. That used to be much quicker...Now it’s that I have to be dressed to protect the skin on my backside. I have to do that kind of ritual stuff in bed and that takes me roughly 20 minutes every morning. It bothers me but I know I need to do it so that there’s no skin breakdown or un-cleanliness or something like that doesn’t cause an issue down the road” (SCI 4; Male with traumatic SCI).

Relatedly, many traumatic SCI participants underscored the importance of being aware of their bodies, with some participants describing the phenomenon of having to rediscover themselves post-injury:

“The thing that most accurately described relating to being in tune with your body is when you get a spinal cord injury you are now two people. There’s the upper part of you and there’s the lower part of you and they don’t communicate with each other. The lower part of you is like a little baby. It’s like it will react but you don’t know what that means because it’s not communicating with you. Like I mean it’s not directly linked to you. You can’t feel it. So you have to interpret what those reactions mean. Just like if a little baby is crying, well why is he crying, what’s going on” (SCI 5; Male with traumatic SCI).

It appeared that caregiver involvement was instrumental to these monitoring activities, especially for skin care:

“But he’ll also be like ‘hey can you look at something it feels a little different’ because he’s very aware by just feeling. He does have mirrors but sometimes just feeling his skin he’s like what’s going on here and then I’ll check it out” (Caregiver 4; Wife of individual with traumatic SCI).

4.3.3.3 Independence-Dependence Conflict

The sub-theme of independence-dependence conflict as a component of self-management emerged chiefly among individuals with traumatic SCI and their caregivers. Participants
described this as being related to their ongoing attempt for independence on the part of individuals with traumatic SCI:

“So what his success is I think it’s just a willingness to live and then to be autonomous and independent and we supported him in all that, in all those aspects and helped him buy a car. Two years after his accident we helped him buy a condo. He wanted to become autonomous. So all the family, especially my parents, were really what can we do to help you do what you want. It didn’t require a lot of constant effort on our part. We were just there when he needed us” (Caregiver 5; Brother of individual with traumatic SCI).

However, it was noted in some instances that in striving for this independence, there was a simultaneous risk of injury: “… two of the times he [individual with traumatic SCI] was very tired, working long hours and did two transfers and ended up in injuries” (Caregiver 4; Wife of individual with traumatic SCI).

4.3.3.4 Self-Management as an Unknown Term

Finally, the term self-management itself was unfamiliar to many of the SCI and caregiver participants. During the interview, the participants’ understanding of self-management was only derived after probing as exemplified by the following questions: “Self manage in terms of what exactly? Can you be more specific in your question? In my daily struggle, in my daily routine?” (SCI 7; Male with traumatic SCI).

4.3.3.5 Directing Someone Else to Provide Your Care

The sub-theme of directing someone else to provide your care (i.e., often a spouse for the prevention of secondary complications) was mainly put forward by acute care/trauma and rehabilitation managers. This sub-theme is encapsulated by the following quote:
“I think that the biggest thing for the spinal cord injury is that whole directing their care and teaching them that what a great skill that is and how important it is because they’re going to have attendants all the time and to understand that part” (Manager 5; Female Rehabilitation Manager).

Managers often linked an individual’s level of injury to his or her self-management abilities/behaviours:

“So I’m going to say for a quadriplegic who is a complete injury it would be directing their own care in that they know how to direct caregivers to provide their care” (Manager 11; Female Rehabilitation Manager).

4.3.3.6 Ownership of Your Own Care/Empowerment in Managing Your Own Care

The sub-theme of ownership of your own care or empowerment in managing your own care emerged as a component of self-management and was shared by all participant groups:

“Then who’s reconnecting with them in the community and whose obligation is that? That sounds harsh but who is responsible. Is the rehab center responsible for how long in that transition? We certainly do follow people and connect with people but if they don’t come back, I can’t. So who owns that. I mean ultimately it’s the patient who owns it I guess. You’ve got to introduce people to it. You’ve got to give them a chance. If they’re never introduced to it, how can they own it?” (Manager 7; Female Rehabilitation Manager).

“I guess I would interpret self-management as taking control of my health and taking the responsibility and making sure that I’m being responsible in terms of dealing with my health, whether it’s making sure that I book my yearly appointments and go to see my doctors. Like I said being proactive if there are issues that do arise, that I’m dealing with it right away and seeking out specialists if that’s needed to assist with whatever treatments or medications or
something that I may need for it. So I think just you know being responsible for yourself” (SCI 1; Female with traumatic SCI).

Several participants believed that the ability to “take control” was associated with the individual’s own intrinsic psychological resources and thus varied from person to person.

4.3.4 External Responsibility Attribution

4.3.4.1 Established Chronic Disease Self-Management Programs

Among acute care and rehabilitation managers, the meaning of self-management in SCI was linked with existing or traditional chronic disease self-management models or programs, such as the Stanford CDSMP:

“But it’s more around the philosophy of like the Stanford model and ownership of the chronic disease model. It’s a self-management model. That is what it’s based on” (Manager 7; Female Rehabilitation Manager).

4.3.4.2 Importance of Caregiver Skill Set

Lastly, several participants identified the importance of the caregiver’s own skill set in providing a wide range of support to the individual with SCI (e.g., basic and instrumental activities of daily living and assisting in the prevention/monitoring and/or management of secondary complications). They also linked this to the steps in self-management in SCI. The caregivers’ skill set was also shared across all the participant groups:

“I mean some people will never be able to self-catheterize. So we educate their partner in care as to how they can help to do that. So they need to be taught at the same time as the individual patient. They need to know the risks in particular with you know I’m thinking of bladder dystonia and pressure sores, transferring and all of that. I mean these people aren’t going home to live by themselves. That’s quite rare. So they need to have the support service from their partner in care
and family members and they need as much education as the patient does, sometimes more” (Manager 4; Female Rehabilitation Manager).

“I would have to do his catheter stuff and his bowel routine and all of that. I really wanted to be aware so that if issues came up with nursing, I knew what was involved you know. That was really helpful. There have been times where you know even just from having a full bladder you don’t realize like if you’re not trained that you can look for signs” (Caregiver 2; Wife of individual with traumatic SCI).

4.4 DISCUSSION

This study aimed to understand the meaning of self-management in traumatic SCI from the perspectives of individuals with traumatic SCI and their (mainly) spousal caregivers as well as acute care/trauma and rehabilitation health care (or clinical) managers. The meaning of self-management in SCI related to the two overarching themes of internal responsibility attribution and external responsibility attribution. Furthermore, a clear delineation in the meaning of self-management was noted in the traumatic SCI and caregiver participants (i.e., the SCI-caregiver dyad) versus the manager participants.

There is a paucity of research on responsibility related to disease management and where it does exist, it has been narrow in focus: rehabilitation after a hip fracture (Olsson et al., 2006) and management of musculoskeletal pain (Larsson et al., 2009). Assuming responsibility is a key factor in the first stage of patient activation; the individual has to take responsibility before he/she can play an active part in managing disease (Hibbard et al., 2007). Nevertheless, responsibility attribution among people with chronic illness has not been explored in detail and its influence on self-management has been rarely explored (Audulv et al., 2010).
4.4.1 Meaning of Self-Management in Traumatic Spinal Cord Injury and Caregiver Participants

For individuals with traumatic SCI and their caregivers, the meaning of self-management in SCI was largely related to beliefs/activities that reflected their belief in internal responsibility attribution. The sub-theme of ownership of one’s own care/empowerment in care management was central to the understanding of proper self-management by the traumatic SCI and caregiver participants. It was also described by manager participants, but not to the same extent as it was in the SCI-caregiver dyads. It is argued that the other sub-themes of wellness awareness, monitoring for secondary complications, independence-dependence conflict, and self-management as an unknown term also reflect internal responsibility attribution as some of these sub-themes correspond with the findings on internal responsibility attribution in a recent qualitative study (Audulv et al., 2010). For example, Audulv and colleagues (2010) determined that those individuals who attributed responsibility to internal factors (e.g., beliefs and attitudes that one is an active agent in his or her own life) had a multi-faceted self-management regimen including a wide range of self-management behaviours in order to facilitate physical and mental well-being. It was further determined among those individuals who had a multi-faceted self-management regimen that there was an alternating between reflexive and routine strategies. With a reflexive strategy, self-management is closely evaluated and new information is sought and incorporated with an individual’s own experiences. With a routine strategy, self-management becomes a course of daily habits and routines. Thus, the themes identified by Audulv and colleagues (2010) as being associated with internal responsibility attribution correspond with the sub-themes identified in the current study including monitoring for secondary complications (i.e., multi-faceted self-management regimen), which also involved
specific routines (i.e., routine strategies) and a rediscovery of themselves post-injury (i.e., reflexive strategies), as well as wellness awareness (i.e., multi-faceted self-management regimen in order to facilitate physical and mental well-being). Wellness awareness as a component of the meaning of self-management according to the SCI and caregiver participants will be further discussed below as it contrasts to the manager participants’ meaning of self-management comprising established chronic disease self-management programs.

Finally, the sub-theme of independence-dependence conflict (including striving for independence) emerged as a component of the meaning of self-management and was consistent with the overarching theme of internal responsibility attribution among the traumatic SCI and caregiver participants. This sub-theme also comprised the notion that in striving for independence, individuals with traumatic SCI risked further injury or had experienced additional injuries. Indeed, maintaining independence has been identified as a key component in the definition of self-management and healthy aging in other studies on individuals with neurological conditions (e.g., multiple sclerosis, stroke) (Koch et al., 2004; Ploughman et al., 2012). The sub-theme of the importance of caregiver skill set was observed in both the SCI-caregiver dyads as well as the manager participants, and was the one sub-theme among the SCI-caregiver dyads that related to external responsibility attribution.

4.4.2 Meaning of Self-Management in Acute Care/Trauma and Rehabilitation Managers

For the manager participants, the meaning of self-management was narrower than that perceived by the SCI/caregiver dyads and the overarching theme of internal responsibility attribution that was observed among the SCI-caregiver dyads was not as dominant in this group. The main sub-themes identified among the manager participants related to both internal and external responsibility attribution, which may reflect their belief in combined responsibility
attribution in self-management. The sub-theme of directing someone else to provide your care was central to self-management in the manager participants. This theme relates to internal responsibility attribution as individuals with traumatic SCI were directing their own care and thus active agents in their own care and lives (i.e., rather than allowing others to determine their care). A few of the SCI-caregiver participants also related self-management to directing someone else to provide your care, consistent with the overarching theme of internal responsibility attribution observed in this group. At the same time, the sub-theme of the importance of caregiver skill set also comprised the meaning of self-management and was identified by both the manager and SCI-caregiver participants. Thus, despite the fact that individuals with SCI were directing their caregivers for their own self-management, they were dependent on the caregivers’ skills for this self-management, the latter reflecting external responsibility attribution. Audulv and colleagues (2010) similarly determined that participants who attributed responsibility to external factors cited other people as critical for attaining success in self-management.

Manager participants reported that the meaning of self-management in SCI related to established chronic disease self-management programs, with some of the managers referencing the CDSMP. In the study by Audulv and colleagues (2010), conventional self-management regimens (e.g., symptom control and management) were related to external responsibility attribution. Indeed, although the CDSMP includes several health behaviour topics, the primary focus is on the daily control and management of disease (Lorig & Holman, 2003). In contrast, wellness interventions focus on maximizing health and quality of life (Stuifbergen, 2006). It is argued that the manager participants’ reference to established or traditional chronic disease self-management programs versus the SCI and caregiver participants’ reference to wellness
awareness (as well as their unfamiliarity with the term self-management itself) speaks to the managers’ conventional notion of self-management in a SCI population. Furthermore, wellness/health promotion interventions are resources that allow the individual to choose behaviours to enhance and sustain quality of life within the context of living with a chronic disabling condition. Conversely, interventions primarily oriented toward controlling disease, symptoms, and risk factors have the chronic illness/disease perspective in the foreground, minimizing the wellness perspective and the associated element of patient choice (Stuifbergen et al., 2010). Thus, the managers’ understanding of self-management in SCI as being associated with traditional chronic disease self-management programs is consistent with an external responsibility attribution, while the SCI and caregivers participants’ definition of self-management as comprising wellness awareness and the associated patient choice is consistent with an internal responsibility attribution. It should also be acknowledged that responsibility attribution may be more of a continuum from external to internal, rather than these defined groups of external and internal responsibility attribution. Future research may involve a quantitative examination of potential covariates or predictors to explain these attributions in self-management (e.g., for the development of programs that could be tailored to individual needs). Changes in responsibility attribution over time, particularly among the individuals with traumatic SCI themselves, would also be worthy of further study (Audulv et al., 2010). Lastly, future studies should aim to understand the meaning of self-management in other chronic conditions as it is unknown how generalizable these findings are to them.

4.4.3 Limitations

The current study acknowledges some limitations. In terms of the recruitment procedure, it is likely that a selection bias operated in those participants who agreed to take part in the
research – they may have been healthier and/or had better/more interest in self-management skills than those individuals who chose not to participate. Additionally, all participants had to have a caregiver who was willing to participate. At the same time, a certain level of intrinsic motivation and support is required in order to successfully participate in a self-management program (Bandura, 2004; Kehn & Kroll, 2009; Kooijmans et al., 2013), and thus it could be argued that the appropriate input was obtained for the development of a self-management intervention for individuals with traumatic SCI. The majority of traumatic SCI participants in the current study were male, which is consistent with the epidemiology of population-based studies (e.g., Couris et al., 2010), with female caregivers. However, future research should attempt to focus on the perspective of females with a traumatic SCI as well as the perspectives of male caregivers in order to increase the applicability of the study findings.

4.4.4 Conclusions

The meaning of self-management in SCI related to the two overarching themes of internal responsibility attribution and external responsibility and revealed differences between the meaning of self-management in SCI among individuals with traumatic SCI and their caregivers versus acute care/trauma and rehabilitation managers. Overall, the meaning of self-management among the SCI and caregiver participants related principally to internal responsibility attribution. For the manager participants, the meaning of self-management was much narrower and the overarching theme of internal responsibility attribution that was observed among the SCI-caregiver dyads was not as widely expressed by this group. The sub-themes identified among the manager participants related to both internal and external responsibility attribution, which may reflect their belief in combined responsibility attribution in self-management in SCI. Furthermore, it is important to note that responsibility attribution may be
more of a continuum from external to internal rather than the clearly defined groups discussed in the current study.

Interventions that are co-created by users and health care professionals are associated with positive physical and mental health outcomes (Bodenheimer et al., 2005). Thus, the understanding of self-management from these varying perspectives could be applied to the development of a tailored self-management program that is associated with outcomes that are relevant to individuals with traumatic SCI and their family members/caregivers. This may involve the development of a program that uses some of the structure of traditional chronic disease self-management programs, in accordance with the beliefs held by the managers of the current study, but also incorporates elements of wellness/health promotion interventions, and ultimately focuses on enabling the empowerment of individuals with traumatic SCI and their caregivers.
Table 4.1: Interview Guide for Meaning of Self-Management in Individuals Traumatic Spinal Cord Injury, their Family Members/Caregivers, and Acute Care/Trauma and Rehabilitation Managers (Example: Individuals with Traumatic SCI Guide)

<table>
<thead>
<tr>
<th>Examples of Open-Ended Questions from Interview Guide</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Walk me through what you are currently doing to manage your condition?</td>
</tr>
<tr>
<td>2. How do you know you’re doing ok; that you can carry on your daily activities; are you satisfied with how you’re performing your daily activities?</td>
</tr>
<tr>
<td>3. What is self-management from your perspective (what comes to mind when you hear the phrase self-management)? <em>Probe: What is the ultimate goal of self-management?</em></td>
</tr>
<tr>
<td>4. What are you currently doing to prevent any secondary complications, that is, any medical conditions that arise as a result of your spinal cord injury, such as urinary tract infections or pressure ulcers? <em>Example of Probes: How so? Tell me more about that.</em></td>
</tr>
</tbody>
</table>


Table 4.2: Characteristics of Individuals with Traumatic SCI

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N=7; n, Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
</tr>
<tr>
<td>Female</td>
<td>1</td>
</tr>
<tr>
<td>Age</td>
<td>39-68</td>
</tr>
<tr>
<td>Time since injury (years)</td>
<td>2-25</td>
</tr>
<tr>
<td>Level of injury</td>
<td></td>
</tr>
<tr>
<td>Paraplegia</td>
<td>5</td>
</tr>
<tr>
<td>Quadriplegia</td>
<td>2</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>&lt;High School</td>
<td>2</td>
</tr>
<tr>
<td>Undergraduate/college</td>
<td>4</td>
</tr>
<tr>
<td>Post-graduate</td>
<td>1</td>
</tr>
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<td>Employment Status</td>
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</tr>
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<td>Unemployed/retired</td>
<td>5</td>
</tr>
<tr>
<td>Part-time</td>
<td>1</td>
</tr>
<tr>
<td>Full-time</td>
<td>1</td>
</tr>
<tr>
<td>Theme</td>
<td>Sub-themes</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td>Internal Responsibility Attribution</td>
<td>Wellness awareness</td>
</tr>
<tr>
<td></td>
<td>Monitoring for secondary complications</td>
</tr>
<tr>
<td></td>
<td>Independence-dependence conflict</td>
</tr>
<tr>
<td></td>
<td>Self-management as an unknown term</td>
</tr>
<tr>
<td></td>
<td>Directing someone else to provide your care</td>
</tr>
<tr>
<td></td>
<td>Ownership of your own care/empowerment in managing your own care</td>
</tr>
<tr>
<td>External Responsibility Attribution</td>
<td>Established chronic disease self-management programs</td>
</tr>
<tr>
<td></td>
<td>Importance of caregiver skill set</td>
</tr>
</tbody>
</table>
Figure 4.1: Meaning of Self-Management in Individuals with Traumatic Spinal Cord Injury according to Individuals with Traumatic Spinal Cord Injury and their Spousal Caregivers and Acute Care/Trauma and Rehabilitation Managers.
Abstract

**Study Design:** Cross-sectional survey.

**Objective:** To determine the relevant components of a self-management program for individuals with traumatic spinal cord injury (SCI).

**Setting:** Community setting, Canada.

**Methods:** Individuals with SCI were recruited by email via the Rick Hansen Institute (Vancouver, British Columbia, Canada) as well as an outpatient hospital spinal clinic. Data were collected by self-report using an on-line survey.

**Results:** A response rate of 48% was achieved (n=99). The components of a self-management program that were rated as “very important” by the greatest proportion of participants included: exercise (n=53; 53.5%), nutrition (n=51; 51.5%), pain management (n=44; 44.4%), information/education on aging with a SCI (n=42; 42.4%), communicating with health care professionals (n=40; 40.4%), problem solving (n=40; 40.4%), transitioning from rehabilitation to the community (n=40; 40.4%), and confidence (n=40; 40.4%). Overall, 74.7% (n=74) of the sample rated the overall importance of the development of a self-management program for individuals with traumatic SCI as “very important” or “important”. Almost 40% (n=39) of the sample indicated a preference for an internet-based self-management program. The highest proportion of participants indicated a preference for having individuals with a similar level of
injury \( n=74; 74.7\% \); a preference for having individuals of a similar age \( n=40; 40.4\% \) was also noted.

**Conclusion:** The importance assigned to the modules on exercise and nutrition is consistent with our previous, qualitative research and a wellness/health promotion approach for self-management in this population. This research could be used to develop and pilot test a self-management program for individuals with traumatic SCI.
5.1 INTRODUCTION

The trend of decreasing length of stay in rehabilitation facilities has led to individuals with spinal cord injury (SCI) entering the community with fewer self-care skills to prevent secondary complications (Chen et al., 1999; McColl et al., 2012). Families and others comprising their informal support network also have less time to adjust. As a result, there is evidence to suggest that these reduced lengths of stay in rehabilitation and associated consequences lead to higher rates of secondary complications and subsequent high rehospitalization rates (Jones & Evans, 1998; Jaglal et al., 2009; Munce et al., 2009). Given this increasing emphasis on the community management of SCI, strategies that could be developed and implemented in order to increase patients’ involvement and control of their medical treatment and its subsequent effects are required (Kroll et al., 2007). A self-management program could be one approach to address these complex needs, including secondary complications.

Hirsche and colleagues (2011) recently conducted a qualitative study on the experiences of individuals with neurological conditions, including stroke, multiple sclerosis, and SCI, who participated in the Stanford Chronic Disease Self-Management Program (CDSMP). The CDSMP is one of the most validated and widely used programs (Lorig et al., 1999; 2001). The program is consistent with Bandura’s self-efficacy theory, a social cognitive theory that states that the key predictors of successful behaviour change are confidence (self-efficacy) in the ability to carry out an action and expectation that a particular goal will be achieved (outcome expectancy). The CDSMP covers generic topics including: an overview of self-management principles, exercise, pain and fatigue management, relaxation techniques (e.g., guided imagery and breathing exercises), dealing with depression, nutrition, communicating with family and
health professionals, problem solving, and goal setting. The study by Hirsche and colleagues (2011) was the first study to examine the experience or the effect of the CDSMP on individuals with SCI. Individuals with SCI as well as the individuals leading the self-management program in this study suggested the need for a SCI-focused group (e.g., individuals with SCI needed information specific to and modules adopted for being in a wheelchair/reduced mobility). In addition, they also found that when attendant care is an important component, as is the case in individuals with SCI, a different approach may be needed to teach self-management skills (i.e., being a good director of care, instead of a person who manages care independently) (Hirsche et al., 2011). Specific self-management programs have been developed for other chronic diseases including arthritis (e.g., Arthritis Self-Management Program) (Lorig et al., 2005) and stroke (e.g., Moving on After Stroke) (Taylor et al., 2012). Collectively, these findings point to the need for both greater understanding of self-management in SCI and details on the specific components of a self-management program desired by individuals with SCI. Thus, the objective of the current study is to determine the relevant components of a self-management program for individuals with traumatic SCI. This is first study of its kind to consider such components and is the third of a four part study on the considerations for the development of a tailored self-management program for individuals with traumatic SCI.

5.2 METHODS

5.2.1 Study Design

A national, cross-sectional study was conducted including individuals with traumatic SCI living in the community in Canada. Research ethics approval was obtained from the University of Toronto (Protocol Reference #26429). All participants provided informed consent prior to completing the survey.
5.2.2 Participants and Recruitment

Eligible participants included individuals who 1) had experienced a traumatic SCI (e.g., a fall, motor vehicle accident, sporting accident, etc); 2) were 18 years of age or older; and, 3) were fluent in English. Participants were recruited by email via the Rick Hansen Institute (RHI) and included individuals who had previously agreed to be contacted for research purposes. RHI is a Canadian-based not-for-profit organization “committed to accelerating the translation of discoveries and best practices into improved treatments for people with SCI” (RHI, 2013). Additional participants were recruited in person via the outpatient spinal clinic at Toronto Western Hospital. All participants were recruited between January and June 2013.

5.2.3 Data Collection and Survey Items

Data were collected by self-report surveys using on-line software, FluidSurveys (http://fluidsurveys.com/surveys/sarah-munce/sci-self-management-survey/?ef). The specific content of the survey itself was based on the themes that emerged in the first phase of this study on the facilitators and barriers to self-management in traumatic SCI (i.e., influence of positive/negative mood, self-efficacy) (see Munce et al., accepted, BMC Neurology, March, 2014) as well as the relevant psychological elements (i.e., module on depression)/underlying theory of the CDSMP (i.e., social cognitive theory and self-efficacy).

Participants were asked to rate the importance of various suggested modules (i.e., content) as well as the overall importance of a self-management program for individuals with traumatic SCI on a Likert scale with five response options (1=very unimportant, 5=very important). These suggested modules were based on the themes from our previous, qualitative research on the perceived facilitators and barriers to and meaning of self-management in traumatic SCI (e.g., importance of positive outlook and acceptance/difficulties achieving positive
outlook or mood, and maintaining independence/control over care) (see Munce et al., accepted, BMC Neurology, March, 2014; see Munce et al., submitted, Disability and Rehabilitation, December, 2013) as well as the existing modules in the CDSMP (e.g., exercise, pain management, fatigue management). In addition, participants were asked to indicate their preferred modes of delivery (e.g., internet-based, telehealth system, a series of DVDs), format (e.g., one-on-one, in a group setting), program make-up (e.g., individuals of a similar age, individuals of a similar gender, individuals with a similar level of injury), timing (e.g., during the acute care period, during the rehabilitation period, during the transition from rehabilitation to the community), follow-up periods (e.g., meet again as a group one or two years after the completion of the first program, regular contact with individuals from the group, regular contact with a health care professional) program leader(s) (e.g., health care professional(s) such as a nurse, non-health care professionals, individual(s) who has/have a traumatic SCI), and program organizer(s) (e.g., family physician, physiatrist, case manager).

Standardized questionnaires were used to capture these themes from the first phase of the study/relevant elements of the CDSMP and were embedded within the larger survey. The relevant questionnaires to this study included the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) and the Patient Activation Measure (PAM) (Hibbard et al., 2004; Hibbard et al., 2005).

5.2.3.1 The Hospital Anxiety and Depression Scale (HADS)

The HADS is a brief, self-report measure that was designed to detect the presence and severity of relatively mild degrees of mood disorder in non-psychiatric, hospital outpatients. It provides separate scores for anxiety and depression. The HADS has 14 items (seven for anxiety and seven for depression) and has established reliability and validity (Bjelland et al., 2002).
Scores range from 0 to 21, with higher scores indicating greater anxiety and depression (Zigmond & Snaith, 1983). Cut-off scores of $\geq 8$ have been used previously to denote clinically anxious or depressed mood (Barlow et al., 2009).

**5.2.3.2 The Patient Activation Measure (PAM)**

The PAM is designed to assess an individual’s knowledge, skill, and confidence in managing his or her own health care (Hibbard et al., 2004; Hibbard et al., 2005). It consists of 13 items and uses a Likert agreement scale with four response options (1=strongly disagree, 4=strongly agree). The raw score is calculated by adding all of the responses to the 13 questions and range from 13 to 52. These raw scores are converted into activation scores. The converted activation scores range from 0 to 100. Based on these activation scores, patients are placed into one of four stages of progressive activation: believes active role is important (PAM score of $\leq 47.0$), has the confidence and knowledge to take action (PAM score of 47.1 to 55.1), is taking action (PAM score of 55.2 to 67.0), and is able to stay the course under stress (PAM score of $\geq 67.1$) (PAM, 2007). Previous research has demonstrated that higher PAM scores are associated with healthy behaviours, a higher likelihood of performing self-management, and higher medication adherence (Mosen et al., 2007). Patients scoring at the lower end of the activation may believe that the physician is the one to “fix” them; mid-range scores may indicate that patients recognize that they may be involved in their care, but lack the knowledge to do so effectively. Patients with high PAM scores have gained confidence in their ability to self-manage and make lifestyle changes. The PAM was developed and validated in insured community-based samples in the US (Hibbard et al., 2005; Hibbard & Tusler, 2007).

In addition, socio-demographic and injury-related variables were documented including age, sex, marital status, level of education, level of injury, and time since injury. Multiple
iterations of the survey instrument were produced and reviewed by the research team for flow and content.

5.2.4 Data Analysis

Descriptive statistics on the recruitment of participants, socio-demographic and clinical characteristics (means, median, and percentages) were calculated. The participants who completed the survey and the individuals who failed to complete the survey were compared according to age, sex, and level of injury using independent t-test and Chi-Square test, or Mann-Whitney U-test. This was to determine whether the “completion” group was representative of the larger group of eligible individuals identified for the study. The importance of the various suggested modules (i.e., content) of a self-management program, the preferences related to the delivery, format, program make-up, follow-up periods, program leader(s), program organizer(s), as well as the overall importance of developing a self-management program have been reported as proportions. Statistics were calculated using the statistical package for the social sciences software (SPSS; Version 21.0, IBM, Armonk, NY, USA).

5.3 RESULTS

5.3.1 Response Characteristics and Sample Comparability

Survey invitations were sent to 300 individuals with SCI (i.e., individuals with both traumatic and non-traumatic SCI) from the RHI; additional individuals were approached at the Toronto Western Hospital outpatient spinal clinic (numbers suppressed due to small sample size i.e., ≤ 5). From this, 145 individuals responded to the survey invitation (response rate of approximately 48%); with 114 participants completing the entire survey.

Five individuals had injuries of non-traumatic origin and were therefore excluded (109 individuals with TSCI at this point). A further 10 outliers were excluded due to perfect patient
activation scores (a measure of self-management behaviour), as per the recommendation of Hibbard and colleagues (2004, 2005) yielding a final sample size of 99 individuals.

There were no significant differences between individuals who completed the survey ($n=114$) and individuals who did not complete the survey ($n=31$) in relation to age and gender ($P > 0.05$). However, there was a significant difference between group membership (i.e., individuals who completed the survey and individuals who did not complete the survey) and level of injury (Chi Square (2) = 7.915, $P < 0.05$).

### 5.3.2 Sample Characteristics

Selected sociodemographic and clinical characteristics are presented in Table 5.1. The majority of the sample was male ($n=74; 74.7\%$) and represented a chronic SCI sample with time since injury ranging from $<1$-54 years (mean=$17.5$ years; median=$16$ years). Most participants reported having a family physician ($n=94; 94.9\%$). Among those that had a family physician, the most common reason for a family physician visit in the past 12 months was for bladder dysfunction (e.g., urinary tract infection) ($n=45; 47.9\%$), followed by pain ($n=35; 37.2\%$), and bowel issues ($n=19; 20.2\%$). Eleven percent ($n=10$) of the sample reported that they had visited their family physician in the past 12 months for depression. However, among this group with a family physician, 25.5% of the sample ($n=24$) had a HAD scale depression score consistent with a clinically depressed mood. A third of the sample ($n=33$) reported that they had visited the emergency department in the past 12 months; with bladder dysfunction ($n=9; 27.3\%$) cited amongst the highest proportion of participants, followed by injury ($n=6; 18.2\%$), and pain ($n=5; 15.2\%$). Lastly, in terms of the patient activation levels, 7.1% ($n=7$) of the sample were in the “starting to take a role”, 9.1% ($n=9$) were in the “building knowledge and confidence”, 21.2% ($n=21$) were in the “taking action”, and 62.6% ($n=62$) were in the “maintaining behaviours”
segments. Thirteen percent of participants in the highest activation group had a depression score consistent with a clinically depressed mood (results not tabulated).

5.3.3 Components of a Self-Management Program

The ratings for all of the suggested modules (i.e., content) and overall importance of a self-management program are reported in Table 5.2. The other preferred components including modes of delivery, format, program make-up, timing, follow-up periods, program leader(s), and program organizer(s) have been reported in Table 5.3. Based on all of these findings, a summary of the suggested components of a self-management program for individuals with traumatic SCI is presented in Table 5.4. The components of a self-management program that were rated as “very important” by the greatest proportion of participants included: exercise (n=53; 53.5%), nutrition (n=51; 51.5%), pain management (n=44; 44.4%), information/education on aging with a SCI (n=42; 42.4%), communicating with health care professionals (n=40; 40.4%), problem solving (n=40; 40.4%), transitioning from rehabilitation to the community (n=40; 40.4%), and confidence (in reducing secondary complications/promoting wellness) (n=40; 40.4%). Overall, 74.7% (n=74) of the sample rated the overall importance of the development of a self-management program for individuals with traumatic SCI as “very important” or “important”.

In terms of modes of delivery, 39.4% (n=39) of the sample indicated a preference for an internet-based self-management program, and within this mode of delivery, 29.3% (n=29) indicated a preference for a one-on-one format (i.e., one facilitator to one client). In terms of program make-up, the highest proportion of participants indicated a preference for having individuals with a similar level of injury (n=74; 74.7%); a preference for having individuals of a similar age (n=40; 40.4%) was also noted. The rehabilitation period (n=42; 42.4%) and the transition from rehabilitation to the community (n=29; 29.3%) were the preferred times to
introduce a self-management program. The majority of the sample \((n=88; 88.9\%)\) responded positively about the need for a follow-up session or a follow-up program; 31.3% \((n=31)\) indicated a preference for the follow periods occurring as regular contact with a health care professional. One quarter \((n=25; 25.3\%)\) of the sample indicated a preference for the follow periods occurring as regular contact with an individual(s) from the group. In terms of program leaders, 38.4% \((n=38)\) indicated a preference for both a health care professional and an individual with a traumatic SCI. Lastly, 41.4% \((n=41)\) indicated that an organization such as SCI Canada (a community-based service provider to individuals living with SCI) should organize the self-management program; 37.4% indicated that the rehabilitation team should organize the program.

**5.4 DISCUSSION**

The objective of the current study was to determine the relevant components of a self-management program for individuals with traumatic SCI including preferences related to various suggested modules (i.e., content) and other characteristics including delivery, format, and program make-up. To the best of our knowledge, this is the first study to examine the preferred components of a self-management program specific to individuals with traumatic SCI.

Many of the more preferred modules (i.e., content) for a self-management program were existing modules of the CDSMP, as outlined above, including exercise, nutrition, pain management, communicating with health care professionals, problem solving, and confidence. At the same time, the importance assigned to the modules on exercise and nutrition in the current study is in line with our previous, qualitative research on the meaning of self-management in traumatic SCI. Our research determined that part of the meaning of self-management according to individuals with traumatic SCI and their (mainly family) caregivers included the notion of
“wellness awareness” which included lifestyle practices/changes including good nutrition, vitamin supplementation, exercise, and relaxation that these participants associated with living well and maintaining/optimizing health. Wellness/health promotion interventions (i.e., focusing on exercise and nutrition) are resources that allow the individual to choose behaviours to enhance and sustain quality of life within the context of living with a chronic disabling condition (Stuifbergen et al., 2010), and thus could increase the individual’s sense of control over his or her care (i.e., self-efficacy).

Approximately 40% of the current sample indicated that a module on increasing confidence was “extremely important”, a finding which is consistent with the importance/centrality of self-efficacy in the CDSMP (Lorig et al., 1999; 2001). We also previously determined the importance of the individual with SCI maintaining control over care as an important facilitator to self-management in SCI. Given our previous findings on the importance of positive and negative mood as either a facilitator or barrier to self-management and the fact that one quarter of the current sample had a depression score consistent with a clinically depressed mood, it is surprising that a greater proportion of the current sample did not rate the “dealing with depression” module as “very important”. This finding may be related to the stigma of mental illness/seeking help for mental illness (Fann et al., 2011). Given the fact that the “communicating with health care professionals” module was among the more preferred modules, it is possible that this finding relates to a difficulty introducing the topic of mood/depression, specifically, with a health care professional and a desire for some skills/confidence to introduce the topic. Moreover, the low rate of family physician visits related to depression found in the current study has been previously identified (i.e., Fann et al., 2011) and may be because the ongoing medical concerns of individuals with SCI are given priority
over the emotional concerns of individuals with SCI (Fann et al., 2011). Overall, more research is needed to examine the barriers to care that may be contributing to the low rates of depression treatment in SCI as well as to systematically study treatments for depression (e.g., antidepressants) after SCI.

A module on “information/education on aging with a SCI” was also among the preferred modules. As progress in medical and rehabilitation treatment has improved, patients with more complex needs, including chronic conditions such as diabetes and heart disease, are surviving (Vaidyanathan et al., 1998). Indeed, aging with a SCI was found to be a cross-cutting theme in our previous, qualitative research: aging/chronic conditions were found to be a complicating factor in maintaining positive physical (i.e., secondary complications) and mental health (i.e., mood). Lastly, based on the most commonly cited reasons for a family physician/emergency department visit, modules on (preventing) bowel/bladder dysfunction and injury are recommended, although these were not included as module/content response options on the survey.

For the greatest proportion of participants, an internet-based self-management program was the preferred mode of delivery. Internet-based applications/tools are recognized as having the potential to overcome barriers to self-management skills including cost and access (e.g., delivery independent of time and location) (Owen et al., 2002). We previously highlighted lack of accessibility as one of the barriers to self-management (e.g., accessing buildings, difficulties with accessing physician offices and/or exam tables), and thus the preference for an internet-based program is consistent with overcoming this barrier. On-line self-management programs have previously demonstrated improvements in self-efficacy and patient activation when compared to usual care (e.g., Lorig et al., 2010).
Almost one third of participants indicated a preference for a one-on-one format (i.e., one facilitator to one client, in real time), which may reflect a need/desire for more intensive/individualized support given the potential physical (e.g., secondary complications) and emotional complexities of living with a SCI. At the same time, group programs include the benefit of peer support and opportunities for interaction (Health Council of Canada, 2012). Almost 40% of participants indicated a preference for both a health care professional and an individual with a SCI to deliver the program. This is not unlike other self-management programs which can be led by both a health care professional and a trained peer leader who has the same condition as the participants. Again, this preference may reflect a desire to address both the physical (i.e., via the health care professional) and emotional (i.e., via the peer leader) complexities of a SCI. In terms of program make-up, almost 75% of participants indicated that having individuals with a similar level of injury was important. A preference for a program composed of individuals of a similar age was also noted. The importance of this matching has been recognized in previous studies whereby demographic/clinical information such as age, race, and etiology of injury was considered when assigning a potential mentee to a mentor (Ljunberg et al., 2011). The rehabilitation and/or the transition from rehabilitation to the community period were noted as the preferred times to introduce a self-management program. Given the importance of motivation/readiness to change in self-management (Keller & White, 1997; Levich, 2007; Health Council of Canada, 2012), this represents a key implementation consideration. Lastly, a preference was indicated for an organization such as SCI Canada to organize the program. Given that SCI Canada already organizes a peer support counseling program, it is likely that some existing infrastructure (staff, peer mentors) could be used for the organization of a self-management program.
The current study acknowledges some limitations. Although a national sample was employed, it is likely that the current sample is not representative of the broader group of individuals with traumatic SCI. Instead, it is likely that the current sample represented a more engaged and healthier group of individuals with traumatic SCI (e.g., 95% of the sample reported having a family physician; 62.6% were in the “maintaining behaviours” segment of self-management/activation). However, given that three-quarters of this (relatively healthy) sample believed that the development of a self-management program was “important” or “very important”, it is likely the development of a self-management program in this population is even more warranted among those individuals who are not as high-functioning. Furthermore, the design of the current study is cross-sectional and therefore it is unknown how these perspectives on the components of a self-management program change over time/vary by various stages of the recovery trajectory. Future research should explore how these perspectives/preferences might change over time.

The current study is, to the best of our knowledge, the first of its kind to determine the relevant components of a self-management program for individuals with traumatic SCI. Many of the most preferred modules of a self-management program were existing modules of the CDSMP. At the same time, the importance assigned to the modules on exercise and nutrition is in line with our previous, qualitative research and a wellness/health promotion approach for self-management in this population. Various implementation considerations were determined including the preference for an on-line mode of delivery, likely to address issues of accessibility. Future research might consider how these preference changes over time, but ultimately, this research could be used to develop and pilot test a self-management program for individuals with traumatic SCI.
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<td>Less than high school</td>
<td>11 (11.1)</td>
</tr>
<tr>
<td>High school</td>
<td>25 (25.3)</td>
</tr>
<tr>
<td>Trade certificate/College/University certificate or diploma</td>
<td>32 (32.3)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>21 (21.2)</td>
</tr>
<tr>
<td>Degree above the Bachelor’s degree</td>
<td>10 (10.1)</td>
</tr>
<tr>
<td>Current Province*</td>
<td></td>
</tr>
<tr>
<td>Ontario</td>
<td>34 (34.3)</td>
</tr>
<tr>
<td>British Columbia</td>
<td>21 (21.2)</td>
</tr>
<tr>
<td>Alberta</td>
<td>16 (16.2)</td>
</tr>
<tr>
<td>Other</td>
<td>28 (28.3)</td>
</tr>
<tr>
<td>Have Children</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>60 (60.6)</td>
</tr>
<tr>
<td>No</td>
<td>39 (39.4)</td>
</tr>
<tr>
<td>Primary Caregiver</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>26 (26.3)</td>
</tr>
<tr>
<td>Attendant</td>
<td>23 (23.2)</td>
</tr>
<tr>
<td>No primary caregiver</td>
<td>39 (39.4)</td>
</tr>
<tr>
<td>Other</td>
<td>11 (11.1)</td>
</tr>
<tr>
<td>Home Setting</td>
<td></td>
</tr>
<tr>
<td>Home without health services</td>
<td>58 (58.6)</td>
</tr>
<tr>
<td>Home with health services</td>
<td>17 (17.2)</td>
</tr>
<tr>
<td>Apartment without health services</td>
<td>15 (15.2)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (9.1)</td>
</tr>
<tr>
<td>Level of Injury</td>
<td></td>
</tr>
<tr>
<td>Quadriplegia</td>
<td>38 (38.4)</td>
</tr>
<tr>
<td>Paraplegia</td>
<td>49 (49.5)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>12 (12.1)</td>
</tr>
</tbody>
</table>

*Representative was achieved from 11 of the 13 provinces and territories in Canada.
Table 5.1: Sociodemographic and Clinical Characteristics (continued)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N=99</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time Since Injury</strong>—Mean, (s.d.), range, median</td>
<td></td>
<td>17.5, (12.3), 54, 16</td>
</tr>
<tr>
<td><strong>Etiology</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sport</td>
<td>19 (19.2)</td>
<td></td>
</tr>
<tr>
<td>Fall</td>
<td>15 (15.2)</td>
<td></td>
</tr>
<tr>
<td>Transport or Motor Vehicle Collision</td>
<td>50 (50.5)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>15 (15.2)</td>
<td></td>
</tr>
<tr>
<td><strong>Brain Injury</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7 (7.1)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>88 (88.9)</td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td>4 (4.0)</td>
<td></td>
</tr>
</tbody>
</table>

**Based on 95 participants.
Table 5.2: Importance of Various Suggested Modules (i.e., Content) of a Self-Management Program in Traumatic Spinal Cord Injury

<table>
<thead>
<tr>
<th>Component</th>
<th>Very Unimportant</th>
<th>Unimportant</th>
<th>Neither Important or Unimportant</th>
<th>Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise</td>
<td>--</td>
<td>--</td>
<td>41 (41.4)</td>
<td>53 (53.5)</td>
<td></td>
</tr>
<tr>
<td>Pain management</td>
<td>--</td>
<td>--</td>
<td>8 (8.1)</td>
<td>41 (41.4)</td>
<td>44 (44.4)</td>
</tr>
<tr>
<td>Fatigue Management</td>
<td>--</td>
<td>--</td>
<td>16 (16.2)</td>
<td>50 (50.5)</td>
<td>28 (28.3)</td>
</tr>
<tr>
<td>Relaxation Techniques</td>
<td>--</td>
<td>9 (9.1)</td>
<td>44 (44.4)</td>
<td>32 (32.3)</td>
<td>9 (9.1)</td>
</tr>
<tr>
<td>Dealing with depression</td>
<td>--</td>
<td>--</td>
<td>12 (12.1)</td>
<td>42 (42.4)</td>
<td>34 (34.3)</td>
</tr>
<tr>
<td>Nutrition</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>43 (43.4)</td>
<td>51 (51.5)</td>
</tr>
<tr>
<td>Communicating with family</td>
<td>--</td>
<td>--</td>
<td>17 (17.2)</td>
<td>43 (43.4)</td>
<td>36 (36.4)</td>
</tr>
<tr>
<td>Communicating with HCPs</td>
<td>--</td>
<td>--</td>
<td>8 (8.1)</td>
<td>47 (47.5)</td>
<td>40 (40.4)</td>
</tr>
<tr>
<td>Problem solving</td>
<td>--</td>
<td>--</td>
<td>14 (14.1)</td>
<td>41 (41.4)</td>
<td>40 (40.4)</td>
</tr>
<tr>
<td>Goal setting/action planning</td>
<td>--</td>
<td>--</td>
<td>23 (23.2)</td>
<td>47 (47.5)</td>
<td>24 (24.2)</td>
</tr>
<tr>
<td>Information/education on aging with a SCI</td>
<td>--</td>
<td>--</td>
<td>10 (10.1)</td>
<td>45 (45.5)</td>
<td>42 (42.4)</td>
</tr>
<tr>
<td>Information/education on sexuality and SCI</td>
<td>--</td>
<td>--</td>
<td>24 (24.2)</td>
<td>50 (50.5)</td>
<td>18 (18.2)</td>
</tr>
<tr>
<td>Relationship issues (e.g., with your spouse)</td>
<td>--</td>
<td>--</td>
<td>20 (20.2)</td>
<td>41 (41.4)</td>
<td>32 (32.3)</td>
</tr>
<tr>
<td>Confidence</td>
<td>--</td>
<td>--</td>
<td>13 (13.1)</td>
<td>43 (43.4)</td>
<td>40 (40.4)</td>
</tr>
<tr>
<td>Decision making abilities</td>
<td>--</td>
<td>--</td>
<td>13 (13.1)</td>
<td>47 (47.5)</td>
<td>34 (34.3)</td>
</tr>
<tr>
<td>Can provide mentorship opportunities</td>
<td>--</td>
<td>--</td>
<td>35 (35.4)</td>
<td>43 (43.4)</td>
<td>16 (16.2)</td>
</tr>
<tr>
<td>Can receive mentorship opportunities</td>
<td>--</td>
<td>--</td>
<td>35 (34.9)</td>
<td>40 (40.4)</td>
<td>18 (18.2)</td>
</tr>
<tr>
<td>Learning about volunteer opportunities</td>
<td>--</td>
<td>--</td>
<td>48 (48.5)</td>
<td>29 (29.3)</td>
<td>11 (11.1)</td>
</tr>
<tr>
<td>Skills to enter/re-enter to job market</td>
<td>--</td>
<td>--</td>
<td>20 (20.2)</td>
<td>36 (36.4)</td>
<td>33 (33.3)</td>
</tr>
<tr>
<td>Issues of transitioning from rehabilitation to the community</td>
<td>--</td>
<td>--</td>
<td>15 (15.2)</td>
<td>37 (37.4)</td>
<td>40 (40.4)</td>
</tr>
<tr>
<td>Overall importance</td>
<td>25 (25.3)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>34 (34.3)</td>
<td>40 (40.4)</td>
</tr>
</tbody>
</table>

--Numbers suppressed due to cell counts of ≤5.
Abbreviations: SCI, Spinal Cord Injury; HCP, Health Care Professional.
Table 5.3: Components of a Self-Management Program in Traumatic Spinal Cord Injury

<table>
<thead>
<tr>
<th>Component</th>
<th>N=99 n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mode of Delivery</strong></td>
<td></td>
</tr>
<tr>
<td>Internet-based</td>
<td>39 (39.4)</td>
</tr>
<tr>
<td>A series of DVDs</td>
<td>7 (7.1)</td>
</tr>
<tr>
<td>In person, in the community</td>
<td>30 (30.3)</td>
</tr>
<tr>
<td>Other (telehealth system, brochure, by telephone, etc)</td>
<td>23 (11.9)</td>
</tr>
<tr>
<td><strong>Format</strong></td>
<td></td>
</tr>
<tr>
<td>One-on-one (i.e., one facilitator to one client)</td>
<td>29 (29.3)</td>
</tr>
<tr>
<td>Individually (e.g., the client views a webinar individually)</td>
<td>22 (22.2)</td>
</tr>
<tr>
<td>In a group setting with other individuals with traumatic spinal cord injury</td>
<td>10 (10.1)</td>
</tr>
<tr>
<td>In a group setting with other individuals with traumatic spinal cord injury together with their caregivers</td>
<td>9 (9.1)</td>
</tr>
<tr>
<td>In a group setting with other individuals with traumatic spinal cord injury together with their caregivers, but with opportunities for separate discussions</td>
<td>21 (21.2)</td>
</tr>
<tr>
<td>Other</td>
<td>8 (8.1)</td>
</tr>
<tr>
<td><strong>Program Make-up</strong></td>
<td></td>
</tr>
<tr>
<td>Similar age (=yes)</td>
<td>40 (40.4)</td>
</tr>
<tr>
<td>Same gender (=yes)</td>
<td>29 (29.3)</td>
</tr>
<tr>
<td>Similar level of injury (=yes)</td>
<td>74 (74.7)</td>
</tr>
<tr>
<td>Individuals with non-traumatic SCI (=yes)</td>
<td>26 (26.3)</td>
</tr>
<tr>
<td>Individuals in a wheelchair (=yes)</td>
<td>28 (28.3)</td>
</tr>
<tr>
<td>Other (=yes)</td>
<td>16 (16.2)</td>
</tr>
<tr>
<td><strong>Timing</strong></td>
<td></td>
</tr>
<tr>
<td>During the acute care period</td>
<td>7 (7.1)</td>
</tr>
<tr>
<td>During the rehabilitation period</td>
<td>42 (42.4)</td>
</tr>
<tr>
<td>During the transition from rehabilitation to the community</td>
<td>29 (29.3)</td>
</tr>
<tr>
<td>Once accustomed to living in the community</td>
<td>11 (11.1)</td>
</tr>
<tr>
<td>Other</td>
<td>10 (10.1)</td>
</tr>
<tr>
<td><strong>Need for Follow-up Sessions or Program</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>88 (88.9)</td>
</tr>
<tr>
<td>No/Don’t know</td>
<td>11 (11.1)</td>
</tr>
<tr>
<td><strong>Follow-up Periods</strong>*</td>
<td></td>
</tr>
<tr>
<td>Meet again as a group 1 or 2 years after</td>
<td>18 (18.2)</td>
</tr>
<tr>
<td>Regular contact with an individual(s) from the group</td>
<td>25 (25.3)</td>
</tr>
<tr>
<td>Regular contact with a health care professional</td>
<td>31 (31.3)</td>
</tr>
<tr>
<td>Other</td>
<td>16 (16.2)</td>
</tr>
</tbody>
</table>

***Based on 90 participants.
Table 5.3: Components of a Self-Management Program in Traumatic Spinal Cord Injury (continued)

<table>
<thead>
<tr>
<th>Component</th>
<th>N=99</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Program Leaders</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health care professional (e.g., nurse, rehabilitation specialist)</td>
<td>38</td>
<td>(38.4)</td>
</tr>
<tr>
<td>Individual(s) who has/have a traumatic spinal cord injury</td>
<td>19</td>
<td>(19.2)</td>
</tr>
<tr>
<td>Combination of any of the choices above</td>
<td>38</td>
<td>(38.4)</td>
</tr>
<tr>
<td>Other (e.g., non-health care professionals, individual(s) who has/have a neurological conditions)</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td><strong>Program Organizers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family physician</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>Case manager</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>Staff in the acute care team</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>Staff in the rehabilitation team</td>
<td>37</td>
<td>(37.4)</td>
</tr>
<tr>
<td>An organization such as the Canadian Paraplegic Association</td>
<td>41</td>
<td>(41.4)</td>
</tr>
<tr>
<td>Staff in the home care team</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>(8.1)</td>
</tr>
</tbody>
</table>

--Numbers suppressed due to cell counts of ≤5.
Table 5.4: Summary of the Suggested Components of a Self-Management Program for Individuals with Traumatic Spinal Cord Injury

<table>
<thead>
<tr>
<th>Component</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Modules (i.e., content)</td>
<td>- Exercise</td>
</tr>
<tr>
<td></td>
<td>- Nutrition</td>
</tr>
<tr>
<td></td>
<td>- Pain management</td>
</tr>
<tr>
<td></td>
<td>- Communicating with health care professionals (e.g., mood) and/or directing care</td>
</tr>
<tr>
<td></td>
<td>- Dealing with depression</td>
</tr>
<tr>
<td></td>
<td>- Problem solving</td>
</tr>
<tr>
<td></td>
<td>- Confidence (i.e., self-efficacy)</td>
</tr>
<tr>
<td></td>
<td>-(Preventing) bowel/bladder dysfunction</td>
</tr>
<tr>
<td></td>
<td>-(Preventing) injury</td>
</tr>
<tr>
<td>Mode of delivery</td>
<td>Internet-based</td>
</tr>
<tr>
<td>Format</td>
<td>One-on-one (i.e., one facilitator to one client)</td>
</tr>
<tr>
<td>Program make-up</td>
<td>Individuals with a similar level of injury, age</td>
</tr>
<tr>
<td>Timing</td>
<td>Rehabilitation or transition from rehabilitation to the community periods</td>
</tr>
<tr>
<td>Follow-up periods</td>
<td>Occurring as regular contact with a health care professional and/or regular contact with an individual(s) from the group</td>
</tr>
<tr>
<td>Program leaders</td>
<td>Health care professional and an individual with a traumatic SCI</td>
</tr>
<tr>
<td>Program organizers</td>
<td>Organization such as Spinal Cord Injury Canada or rehabilitation team</td>
</tr>
</tbody>
</table>
Chapter 6

Paper 4: Examining the Impact of Psychological Characteristics in Self-Management in Individuals with Traumatic Spinal Cord Injury: Results from a National Survey

[Submitted to Disability and Rehabilitation]

Abstract

Study Design: Cross-sectional survey.

Objective: To identify some of the psychological characteristics in self-management (i.e., self-efficacy, mastery, patient activation) that are associated with depression in individuals with a traumatic spinal cord injury (SCI).

Setting: Community setting, Canada.

Methods: Individuals with SCI were recruited by email via the Rick Hansen Institute (Vancouver, British Columbia, Canada) as well as an outpatient hospital spinal clinic. Data were collected by self-report using an on-line survey.

Results: A response rate of 48% was achieved (n=99). Individuals with depression had lower self-efficacy (67.9 versus 94.2, P<.0001), mastery (18.9 versus 22.9, P<.0001), and patient activation (60.4 versus 71.6, P<.0001) as well as higher anxiety (9.0 vs. 5.5, P<.0001), compared to their non-depressed counterparts. A logistic regression determined that lower self-efficacy and mastery scores, as well as less time since injury were associated with depression status (P=.002; P=.024, P=.02 respectively). Individuals with higher anxiety scores were almost 1.5 times more likely to be depressed, while older age was positively associated with depression status (P=.016, P=.024 respectively).
Conclusion: Interventions for depression in SCI (including (a) self-management program/training) should target factors such as self-efficacy and mastery, which in turn, could improve secondary medical complications and overall quality of life.
6.1 INTRODUCTION

Individuals with spinal cord injury (SCI) are predisposed to a range of secondary medical complications including urinary tract infections, pneumonia, pressure ulcers, deep venous thrombosis, spasticity, and pain (Johnson et al., 1998; McKinley et al., 1999; Dryden et al., 2004; Jaglal et al., 2009). Many individuals with SCI will also experience significant psychological, social, and neurobehavioural issues and are at increased risk of developing substance abuse problems, low self-esteem, and depression (Craig et al., 2009). Major (or clinical) depression is the most common psychological condition associated with SCI, affecting approximately 25% to 30% of individuals with SCI living in the community (Craig et al., 2009).

Since the presence or absence of depression can have a significant impact on the recovery trajectory, previous research has identified some risk factors and predictors of depression among individuals with SCI. Overall, however, a paucity of recent research investigating the predictors of depression in SCI has been identified (Arango-Lasprilla et al., 2013). Some of these previously identified factors include younger age (Tate et al., 1994), fewer years of education (Scivoletto et al., 1997; Krause et al., 1999), being unmarried (Tate et al., 1994), unemployment (Kalpakjian & Albright, 2006), pre-injury psychiatric or psychological issues such as substance abuse, and inadequate coping abilities (Pollard & Kennedy, 2007). More recently, Bombardier and colleagues (2012) determined that greater depression severity was associated with being 20 to 29 years of age, not completing high school, not working or attending school, and being ≤ 4 years post-SCI. They also determined that low reinforcement (i.e., experiencing pleasant and rewarding activities) and low self-efficacy were independent predictors of higher depression scores.
The presence of depression in SCI is associated, in turn, with a variety of poorer outcomes including increased hospitalization periods and secondary medical conditions, as well as decreased social integration, quality of life, and self-care dependency (Elliot & Frank, 1996; Elliot & Kennedy, 2004). Indeed, our recent qualitative research determined that positive mood was an important facilitator to self-management, and conversely, that negative mood was an important barrier to self-management, among individuals with traumatic SCI. At the same time, the first part of our results from this national survey on self-management in traumatic SCI revealed that 62.6% were in the “maintaining behaviours” segment of self-management/activation (i.e., the highest level of self-management/activation), despite the fact that 13% of those individuals in this activation group had a depression score consistent with a clinically depressed mood (overall, approximately one quarter of the sample who had reported a family physician visit in the past 12 months had a depression score consistent with a clinically depressed mood). Therefore, the current study aims to explore this complexity and examine the association between relevant psychological characteristics in self-management (i.e., self-efficacy, mastery, patient activation) and depression status in individuals with a traumatic SCI.

6.2 METHODS

6.2.1 Stanford Chronic Disease Self-Management Program and Theory as an Informing Framework

The Stanford Chronic Disease Self-Management Program (CDSMP) and its underlying theory served to inform the current study (as well as the first phase of the study). It is one of the most validated and widely used self-management programs (Lorig et al., 1999; 2001) and is consistent with Bandura’s self-efficacy theory. This is a social cognitive theory that states that the key predictors of successful behaviour change are confidence (self-efficacy) in the ability to
carry out an action and expectation that a particular goal will be achieved (outcome expectancy). Self-efficacy is seen as an early step in causal pathways of behaviour change in self-management programs; increasing self-efficacy is a pre-requisite for behaviour change which, through improved self-management may influence health (e.g., depression) and health care use (e.g., reduce emergency department visits). Specifically, the CDSMP incorporates the mastery experience, role modelling, persuasion, and reinterpretation of physiological and affective states to assist participants in making changes (Bandura, 2004). The CDSMP also covers generic topics including: an overview of self-management principles, exercise, pain and fatigue management, relaxation techniques (e.g., guided imagery and breathing exercises), dealing with depression, nutrition, communicating with family and health professionals, problem solving, and goal setting. Self-efficacy, mastery, and patient activation are the psychological characteristics related to self-management that will be investigated in the current study.

6.2.2 Study Design

A national, cross-sectional study was conducted including individuals with traumatic SCI living in the community in Canada. Research ethics approval was obtained from the University of Toronto (Protocol Reference #26429). All participants provided informed consent prior to completing the survey.

6.2.3 Participants and Recruitment

Eligible participants included individuals who 1) had experienced a traumatic SCI (e.g., a fall, motor vehicle accident, sporting accident, etc); 2) were 18 years of age or older; and, 3) were fluent in English. Participants were recruited by email via the Rick Hansen Institute (RHI) and included individuals who had previously agreed to be contacted for research purposes. RHI is a Canadian-based not-for-profit organization “committed to accelerating the translation of
discoveries and best practices into improved treatments for people with SCI” (RHI, 2013). Additional participants were recruited in person via the outpatient spinal clinic at Toronto Western Hospital. All participants were recruited between January and June 2013.

6.2.4 Data Collection

Data were collected by self-report surveys using on-line software, FluidSurveys (http://fluidsurveys.com/surveys/sarah-munce/sci-self-management-survey/?ef). The specific content of the survey itself was based on the themes that emerged in the first phase of this study on the facilitators and barriers to self-management in traumatic SCI (i.e., influence of positive/negative mood, self-efficacy) (see Munce et al., accepted, BMC Neurology, March, 2014) as well as the relevant psychological elements (i.e., module on depression)/underlying theory of the CDSMP (i.e., social cognitive theory and self-efficacy). Standardized questionnaires were then used to capture these themes/relevant elements and were embedded within the larger survey. They included the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), the Patient Activation Measure (PAM) (Hibbard et al., 2004; Hibbard et al., 2005), the Moorong Self-Efficacy Scale (MSES) (Middleton et al., 2003), and the Pearlin-Schooler Mastery Scale (PMS) (Pearlin & Schooler, 1978). These scales are described below.

6.2.5 Survey Measures and Items

6.2.5.1 The Hospital Anxiety and Depression Scale (HADS)

The HADS is a brief, self-report measure that was designed to detect the presence and severity of relatively mild degrees of mood disorder in non-psychiatric, hospital outpatients. It provides separate scores for anxiety and depression. The HADS has 14 items (seven for anxiety and seven for depression) and has established reliability and validity (Bjelland et al., 2002).
Scores range from 0 to 21, with higher scores indicating greater anxiety and depression (Zigmond & Snaith, 1983). Cut-off scores of ≥8 have been used previously to denote clinically anxious or depressed mood (Barlow et al., 2009).

6.2.5.2 Moorong Self-Efficacy Scale (MSES)

The MSES was developed to measure an individual’s confidence in performing functional, social, leisure, and vocational activities post-SCI (e.g., I can maintain my personal hygiene with or without help). Participants rate their confidence in their ability to complete the 16 tasks on a seven-point Likert scale (1=very uncertain, 7=very certain). The total scale score is obtained by summing the individual item responses and range from 16 to 112. Higher scores indicate higher perceived self-efficacy. Results have confirmed that the MSES is a valid instrument that is sensitive to real-life changes post-SCI (Middleton et al., 2003).

6.2.5.3 The Pearlin-Schooler Mastery Scale (PMS)

The PMS measures global sense of personal control. It consists of seven items and participants respond to a five-point Likert scale about the extent to which they agree (5=strongly agree) or disagree (1=strongly disagree) with statements such as “you can do just about anything you really set your mind to” and “you often feel helpless in dealing with problems of life” (Pearlin & Schooler, 1978). A PMS score ranges from 7 to 35, with a higher score reflecting greater mastery.

6.2.5.4 The Patient Activation Measure (PAM)

The PAM is designed to assess an individual’s knowledge, skill, and confidence in managing his or her own health care (Hibbard et al., 2004; Hibbard et al., 2005). It consists of 13 items and uses a Likert agreement scale with four response options (1=strongly disagree, 4=strongly agree). The raw score is calculated by adding all of the responses to the 13 questions
and range from 13 to 52. These raw scores are converted into activation scores. The converted activation scores range from 0 to 100. Based on these activation scores, patients are placed into one of four stages of progressive activation: believes active role is important (PAM score of \( \leq 47.0 \)), has the confidence and knowledge to take action (PAM score of 47.1 to 55.1), is taking action (PAM score of 55.2 to 67.0), and is able to stay the course under stress (PAM score of \( \geq 67.1 \)) (PAM, 2007). Previous research has demonstrated that higher PAM scores are associated with healthy behaviours, a higher likelihood of performing self-management, and higher medication adherence (Mosen et al., 2007). Patients scoring at the lower end of the activation may believe that the physician is the one to “fix” them; mid-range scores may indicate that patients recognize that they may be involved in their care, but lack the knowledge to do so effectively. Patients with high PAM scores have gained confidence in their ability to self-manage and make lifestyle changes. The PAM was developed and validated in insured community-based samples in the US (Hibbard et al., 2005; Hibbard & Tusler, 2007).

### 6.2.6 Data Analysis

Participants’ sociodemographic and psychological characteristics were compared by depression status using independent \( t \)-test or Mann-Whitney \( U \)-test and Chi-Square test. The participants who completed the survey and the individuals who failed to complete the survey were compared according to age, sex, and level of injury using independent \( t \)-test and Chi-Square test, or Mann-Whitney \( U \)-test. This was to determine whether the “completion” group was representative of the larger group of eligible individuals identified for the study. The presence of outliers was also assessed.

For comparison between depressed and nondepressed groups, Fisher’s exact test or Chi-Square test was used for categorical variables (sex, marital status, education) and \( t \)-test for
continuous variables, including age, anxiety (HADS-Anxiety), and mastery (PMS). Mann-Whitney U-test was used to compare differences in time since injury, self-efficacy (MSES) and patient activation (PAM).

To test for interdependence of the variables, the primary outcome measure of depression (HADS-Depression) and the secondary outcome measures of self-efficacy (MSES), mastery (PMS), patient activation (PAM), anxiety (HADS-Anxiety), time since injury, and age were then determined with Spearman’s correlation coefficient. A logistic regression was performed to examine the individual contribution of the above mentioned independent variables as well as sex, marital status (single versus married/co-habitating), and education (high school or less, bachelor’s/college degree, post-graduate degree) to the dependent variable, depression. Scatterplots and collinearity statistics were initially inspected to determine whether or not the regression data met the assumptions of linearity and normality. The Enter method was adopted, whereby all independent variables were entered into the equation simultaneously. This method was considered appropriate because no theoretical predictions had been made concerning the ordering or importance of the variables in relation to depression (Field, 2009). Statistics were calculated using the statistical package for the social sciences software (SPSS; Version 21.0, IBM, Armonk, NY, USA).

6.3 RESULTS

6.3.1 Response Characteristics and Sample Comparability

Survey invitations were sent to 300 individuals with SCI (i.e., individuals with both traumatic and non-traumatic SCI) from the Rick Hansen Institute; additional individuals were approached at the Toronto Western Hospital outpatient spinal clinic (numbers suppressed due to
small sample size i.e., ≤ 5). From this, 145 individuals responded to the survey invitation (response rate of approximately 48%); with 114 participants completing the entire survey.

Five individuals had injuries of non-traumatic origin and were therefore excluded (109 individuals with TSCI at this point). A further 10 outliers were excluded due to perfect patient activation scores, as per the recommendation of Hibbard and colleagues (2004, 2005) yielding a final sample size of 99 individuals.

There were no significant differences between individuals who completed the survey \(n=114\) and individuals who did not complete the survey \(n=31\) in relation to age and gender \((P > .05)\). However, there was a significant difference between group membership (i.e., individuals who completed the survey and individuals who did not complete the survey) and level of injury (Chi Square \(2\) = 7.915, \(P < .05\)).

### 6.3.2 Sample Characteristics and Sample Characteristics by Depression Status

The overall sample characteristics have been previously reported (Munce et al., submitted, BMC Neurology, December, 2013). Almost one-quarter \(n=24; 24.2\%\) of the sample had a depression score consistent with a clinically depressed mood, while 32.3\% \(n=32\) had a score consistent with a clinically anxious mood (Barlow et al., 2009). In terms of the patient activation levels, 7.1\% \(n=7\) of the sample were in the “starting to take a role”, 9.1\% \(n=9\) were in the “building knowledge and confidence”, 21.2\% \(n=21\) were in the “taking action”, and 62.6\% \(n=62\) were in the “maintaining behaviours” segments. Thirteen percent of participants in the highest activation group had a depression score consistent with a clinically depressed mood (results not tabulated).

The sample characteristics by depression status have been summarized in Table 6.1. Individuals with scores consistent with a clinically depressed mood had significantly poorer
outcomes across all of the psychological variables. For example, individuals with depression had lower self-efficacy (67.9 versus 94.2, \( P<.0001 \)), mastery (18.9 versus 22.9, \( P<.0001 \)), and patient activation (60.4 versus 71.6, \( P<.0001 \)) as well as higher anxiety (9.0 vs. 5.5, \( P<.0001 \)), compared to their non-depressed counterparts. In addition, there was a significant difference with respect to time since injury in the depressed group versus the non-depressed group, with individuals with depression having a mean time since injury of 10.9 years versus 19.8 years in the non-depressed group (\( P=.001 \)).

6.3.3 Associations between Psychological Characteristics

As demonstrated in Table 6.2, there was a significant positive correlation between depression and anxiety (\( r=.545, P<.01 \)), indicating that individuals with higher depression scores had higher anxiety scores. There was a significant negative correlation between depression and self-efficacy (\( r=-.560, P<0.01 \)), indicating that individuals with higher depression scores had lower self-efficacy scores. Characteristics that were significantly (at \( P<.01 \)) associated with time since injury were depression (\( r=-.296, P<.01 \)) and age (\( r=.276, P<.01 \)), suggesting that increased levels of depression were associated with individuals in earlier stages of their injury and older age, respectively.

6.3.4 Characteristics Contributing to Depression

Multicollinearity statistics revealed no high intercorrelations (that is, \( r > 0.70 \)) between the psychological and other variables of interest. Thus, nine independent variables were included in the final logistic regression model: self-efficacy, mastery, patient activation, anxiety, time since injury, and age as well sex, marital status, and education. Results of the logistic regression are shown in Table 6.3. The combination of these nine independent variables accounted for 74% of the variance in this samples’ depression level (adjusted \( R^2=0.742 \)). Of the
nine variables, self-efficacy, mastery, anxiety, time since injury, and age were statistically significant. Lower self-efficacy and mastery scores, as well as less time since injury were associated with depression status \((P=0.002; P=0.024, P=0.02\) respectively). Individuals with higher anxiety scores were almost 1.5 times more likely to be depressed, while older age was positively associated with depression status \((P=0.016, P=0.024\) respectively).

6.4 DISCUSSION

The current study aimed to identify some of the psychological characteristics (i.e., self-efficacy, mastery, patient activation) in self-management that are associated with depression in individuals with a traumatic SCI. A main finding of the current study was that both lower self-efficacy (in performing functional activities of daily living) and mastery (i.e., two key psychological characteristics in self-management, as previously described) were associated with depression status in individuals with traumatic SCI. Lower self-efficacy, as measured by the Lorig Chronic Disease Self-Management Scale (Lorig et al., 2001), has previously been associated with higher depression scores/depressive symptoms in SCI (Pang et al., 2009; Bombardier et al., 2012). In fact, individuals with SCI who have lower self-efficacy demonstrate poorer mental health in general (Kennedy et al., 2012) and increased secondary complications (Suzuki et al., 2007) (i.e., poorer self-management). Indeed, self-efficacy is the foundational element of the Stanford CDSMP (Lorig et al., 1999; 2001) and self-efficacy is seen as an early step in causal pathways of behaviour change in self-management programs, leading to improved health outcomes (e.g., depression). Similarly, a lower mastery score was also associated with depression status, and to the best of our knowledge, this direct association has not been previously investigated in a SCI population. However, Kinder and colleagues (2005) previously outlined a model of ‘hardiness’ in SCI and defined it as taking responsibility to make decisions
for one’s own life (control), demonstrating commitment to choices one makes (commitment), and constructing possibilities and alternatives to problems (challenge). The authors determined that in those demonstrating (high) ‘hardiness’ qualities, control related to the ability to make decisions based on choices of care, commitment was based on achieving individual goals and sustaining independence, and challenge related to solving problems and achieving mastery. Mastery experience (i.e., actual performance of a behavior or task) is believed to be the most powerful source of information influencing self-efficacy (Bandura et al., 2004). Successful performance leads to increased self-efficacy whereas repeated failures may result in lower self-efficacy. An important caveat to these associations is that successful performance must be attributed to one’s own efforts and abilities. Future research should continue to explore the role of mastery in SCI and its impact on other mental health outcomes. Although there is an overall lack of research on the treatment of depression (i.e., psychological interventions) following SCI (Elliot & Kennedy, 2004; Post & van Leeuwen, 2012), future interventions should focus on self-efficacy and (coping) skills as a means of improving depression. This could be accomplished via coping effectiveness training, which has demonstrated some impact in terms of decreasing depression (Kennedy et al., 2003). This training could be incorporated into a self-management program or offered as a separate intervention.

Almost one third of the current sample had a score consistent with a clinically anxious mood. In a review of psychosocial issues in SCI, Post and van Leeuwen (2012) indicated that six studies had examined anxiety in SCI (Kennedy & Rogers, 2000; Kennedy & Evans, 2001; Woolrich et al., 2006; Kennedy et al., 2009; Migliorini & Tonge, 2009; Kennedy et al., 2010). Clinically significant symptoms of anxiety in SCI have been previously reported as ranging from 13.2% to 40%. The current study also determined that a higher anxiety score was significantly
associated with depression. More recently, Ullrich and colleagues (2013) demonstrated that among veterans with SCI and depression, 70% were diagnosed with another psychiatric illness, with post-traumatic stress disorder and other anxiety disorders being the most common (although in this case, these co-morbid disorders are mostly likely related to their combat experience). Thus, interventions for depression in SCI, including (a) self-management program/training, should consider and address the high likelihood of concurrent anxiety.

Patient activation (i.e., knowledge, skills, and confidence for self-management) was not significantly associated with depression status in the logistic regression. However, as previously reported, 62.6% (n=62) of the current sample were in the “maintaining behaviours” segment of patient activation/self-management (self-reported, as determined by the PAM). This proportion was inconsistent with previous findings from a national (US) sample on individuals 45 years and older, demonstrating 22% were in the “maintaining behaviours” segment of patient activation/self-management (Hibbard et al., 2005; Hibbard & Tusler, 2007). Rask and colleagues (2009) similarly determined that 62.2% of their participants were in the highest activation segment in their study of predominantly African American, economically disadvantaged individuals with diabetes. Consistent with the conclusions of Rask and colleagues (2009), future research is needed to confirm the findings related to patient activation and depression in the present study, and explore the use of modified activation measures that might better distinguish between levels of readiness for effective self-management among individuals with (traumatic) SCI, specifically. Nonetheless, patient activation and depression were moderately correlated (i.e., $r=-0.311, P<0.01$), and the bivariate analysis demonstrated significantly lower activation scores among the depressed group versus the non-depressed group. Further large-scale research would allow more advanced analyses, such as structural equation
modeling, to better estimate the relationships between self-efficacy, mastery, patient activation (i.e., self-management behavior), and depression.

Finally, the current study demonstrated that a decreased time since injury and older age were significantly associated with depression status. The nature of these associations has been reported inconsistently in the literature. For example, Krause and colleagues (2000) reported that individuals with SCI were more likely to suffer from depression with increasing age (consistent with the current study) and a greater number of years post-injury (inconsistent with the current study). Tate and colleagues (1994) reported that younger age was associated with depression in SCI. The current findings do appear to mirror the findings of our previous, qualitative research whereby individuals with SCI reported low mood (and/or a lack of readiness for self-management) early in the course of their recovery. Relatedly, Pang and colleagues (2009) demonstrated that those individuals with increased time since injury have better self-efficacy, but the results did not reach statistical significance. They concluded that it may take time for the newly injured individual to accept his or her own disabilities and learn to cope with the consequences of the condition. It was further suggested that as time progresses, individuals with SCI may come to terms with their own disability and thus develop a better sense of control, and in turn, increased mood. Thus, timing of support for depression (and self-management) should be considered (e.g., acute phase of recovery may be too early). In our previous research, individuals with traumatic SCI and their caregivers and health care professionals reported on the increasing complexities of SCI as individuals live longer, with chronic diseases. Thus, it is plausible that with increasing co-morbidities as individuals with SCI age, they are at an increased risk of depression.
The current study acknowledges some limitations. Although a national sample was employed, it is likely that the current sample is not representative of the broader group of individuals with traumatic SCI. Instead, it is likely that the current sample represented a more engaged and healthier group of individuals with traumatic SCI (e.g., approximately 63% of the sample was assigned to the highest patient activation level; 95% of the sample reported having a family physician). Furthermore, the design of the current study is cross-sectional and therefore cannot draw causal links between depression and the psychological characteristics of interest. Longitudinal research is needed to establish causality and understand changes in mood levels among individuals with SCI over time. Finally, the reliance on self-report measures of psychological outcome are considered to be subjective, and thus presented a testing bias. Future SCI research could therefore incorporate clinician-based ratings, consistent with recommendations for clinical trials (Bryce et al., 2007).

In summary, the current study aimed to explore the complexities of the associations between psychological factors relevant to self-management (e.g., self-efficacy, mastery) and depression. Our previous qualitative research demonstrated that (positive/negative) mood was an important facilitator and barrier to self-management. Furthermore, we previously reported that even though the majority of the sample was in the highest activation segment for self-management, a relatively high proportion had a depression score consistent with a clinically depressed mood (i.e., in the current sample, it could be interpreted that, using the PAM, high activation level is irrelevant to depression status). Given this emerging importance of depression (versus patient activation using the PAM), we aimed specifically to further identify the psychological characteristics relevant to self-management that might be associated with depression. Based on the current findings, low self-efficacy and low mastery were significantly
associated with depression, which is consistent with the foundational role that self-efficacy, in particular, plays in many self-management programs. A higher anxiety score, less time since injury, and older age were also significantly associated with depression. Although future, large-scale research is needed to better estimate the relationships between self-efficacy, mastery, patient activation (i.e., self-management behavior), and depression, the current study suggests that interventions for depression in SCI, including (a) self-management program/training, should target factors such as self-efficacy and mastery to improve depression in SCI which could, in turn, improve other outcomes including secondary medical complications and overall quality of life.
Table 6.1: Sociodemographic, Clinical, and Psychological Characteristics by Depression Status

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Depressed (N=24) n (%) or mean (s.d.)</th>
<th>Not Depressed (N=75) n (%) or mean (s.d.)</th>
<th>Total (N=99) n (%) or mean (s.d.)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>53.3 (10.9)</td>
<td>49.6 (12.3)</td>
<td>50.5 (12.0)</td>
<td>.198</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>19 (79.2)</td>
<td>55 (73.3)</td>
<td>74 (74.7)</td>
<td>.788</td>
</tr>
<tr>
<td>Female</td>
<td>5 (20.8)</td>
<td>20 (26.7)</td>
<td>25 (25.3)</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td>.644</td>
</tr>
<tr>
<td>Single</td>
<td>12 (50.0)</td>
<td>33 (44.0)</td>
<td>45 (45.5)</td>
<td></td>
</tr>
<tr>
<td>Married/Co-habitating</td>
<td>12 (50.0)</td>
<td>42 (56.0)</td>
<td>54 (54.5)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td>.945</td>
</tr>
<tr>
<td>High school or less</td>
<td>12 (50.0)</td>
<td>37 (49.3)</td>
<td>49 (49.5)</td>
<td></td>
</tr>
<tr>
<td>Bachelor's/College degree</td>
<td>10 (41.7)</td>
<td>30 (40.0)</td>
<td>40 (40.4)</td>
<td></td>
</tr>
<tr>
<td>Post-graduate degree</td>
<td>2 (8.3)</td>
<td>8 (10.7)</td>
<td>10 (10.1)</td>
<td></td>
</tr>
<tr>
<td>Time since injury (in years)</td>
<td>10.9 (9.0)</td>
<td>19.8 (12.5)</td>
<td>17.5 (12.3)</td>
<td>.001</td>
</tr>
<tr>
<td>Anxiety (HADS)</td>
<td>9.0 (3.1)</td>
<td>5.5 (3.1)</td>
<td>6.4 (3.4)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Knowledge, Skills and Confidence for Self-management (PAM)</td>
<td>60.4 (12.3)</td>
<td>71.6 (12.6)</td>
<td>68.9 (13.3)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>SCI-specific Self-efficacy (MSES)</td>
<td>67.9 (17.2)</td>
<td>94.2 (14.0)</td>
<td>87.8 (18.6)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Mastery (PMS)</td>
<td>18.9 (3.4)</td>
<td>22.9 (3.6)</td>
<td>21.9 (3.9)</td>
<td>&lt;.0001</td>
</tr>
</tbody>
</table>

Abbreviations: HAD, Hospital Anxiety and Depression Scale (HADS); MSES, Moorong Self-Efficacy Scale; PAM, Patient Activation Measure; PMS, Pearlin-Schooler Mastery Scale.
Table 6.2: Correlational Matrix for the Different Outcome Measures

<table>
<thead>
<tr>
<th>Variables</th>
<th>Depression</th>
<th>Anxiety</th>
<th>Knowledge, skills and confidence for self-management</th>
<th>Self-efficacy</th>
<th>Mastery</th>
<th>Time since injury</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>.545**</td>
<td>-.311**</td>
<td></td>
<td>-.560**</td>
<td>-.459**</td>
<td>-.296**</td>
<td>.129</td>
</tr>
<tr>
<td>Knowledge, skills and confidence for self-management</td>
<td>- .244*</td>
<td>- .315**</td>
<td>.369**</td>
<td>.264**</td>
<td>.169</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCI-specific</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-efficacy</td>
<td></td>
<td></td>
<td></td>
<td>.423**</td>
<td>.215*</td>
<td>-.094</td>
<td></td>
</tr>
<tr>
<td>Mastery</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.090</td>
<td>-.043</td>
<td></td>
</tr>
<tr>
<td>Time since injury</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.276**</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**P<.01 (two-tailed) *P<.05 level (two-tailed).
Table 6.3: Logistic Regression with Depression as the Dependent Variable

<table>
<thead>
<tr>
<th>Predictors</th>
<th>B</th>
<th>SE</th>
<th>Wald</th>
<th>df</th>
<th>Sig.</th>
<th>Odds Ratio</th>
<th>95% Lower CI</th>
<th>95% Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCI-specific Self-efficacy</td>
<td>-.097</td>
<td>.032</td>
<td>9.217</td>
<td>1</td>
<td>.002</td>
<td>.908</td>
<td>.853</td>
<td>.966</td>
</tr>
<tr>
<td>Mastery</td>
<td>-.332</td>
<td>.147</td>
<td>5.110</td>
<td>1</td>
<td>.024</td>
<td>.718</td>
<td>.538</td>
<td>.957</td>
</tr>
<tr>
<td>Patient activation</td>
<td>-.035</td>
<td>.037</td>
<td>.894</td>
<td>1</td>
<td>.345</td>
<td>.966</td>
<td>.898</td>
<td>1.038</td>
</tr>
<tr>
<td>Anxiety</td>
<td>.381</td>
<td>.158</td>
<td>5.775</td>
<td>1</td>
<td>.016</td>
<td>1.463</td>
<td>1.073</td>
<td>1.996</td>
</tr>
<tr>
<td>Time since injury</td>
<td>-.089</td>
<td>.038</td>
<td>5.400</td>
<td>1</td>
<td>.020</td>
<td>.915</td>
<td>.849</td>
<td>.986</td>
</tr>
<tr>
<td>Age</td>
<td>.081</td>
<td>.036</td>
<td>5.090</td>
<td>1</td>
<td>.024</td>
<td>1.084</td>
<td>1.011</td>
<td>1.163</td>
</tr>
<tr>
<td>Sex (1=male; 2=female)</td>
<td>-1.197</td>
<td>1.219</td>
<td>.965</td>
<td>1</td>
<td>.326</td>
<td>.302</td>
<td>.028</td>
<td>3.294</td>
</tr>
<tr>
<td>Marital Status (1=single; 2=married/co-habitating)</td>
<td>-.477</td>
<td>.962</td>
<td>.246</td>
<td>1</td>
<td>.620</td>
<td>.621</td>
<td>.094</td>
<td>4.091</td>
</tr>
<tr>
<td>Education (1=high school or less; 2=college/bachelor’s degree; 3=post-graduate degree)</td>
<td>1.756</td>
<td>1.109</td>
<td>2.509</td>
<td>1</td>
<td>.113</td>
<td>5.792</td>
<td>.659</td>
<td>50.891</td>
</tr>
</tbody>
</table>

Abbreviation: CI, confidence interval.
Chapter 7
Discussion

The purpose of this chapter is to 1) summarize the four studies of this thesis; 2) synthesize the two phases of the thesis (i.e., Table 7.1 and Figure 7.1); 3) discuss the strengths and limitations of this research; 4) outline suggestions for future research in self-management and SCI; and, 5) describe the knowledge translation/implementation science and clinical implications of this thesis.

7.1 Summary of the Four Studies

The overall purpose of this thesis was to determine the implementation considerations for the development of self-management program for individuals with traumatic SCI. Collectively, the findings from all four studies contribute to a better understanding of self-management for individuals with traumatic SCI and the patient preferences/key considerations for a self-management program.

7.1.1 Study One

In the first qualitative study, the purpose was to understand the perceived facilitators and barriers to self-management to prevent secondary complications in individuals with traumatic SCI from the perspectives of individuals with traumatic SCI, their family members/caregivers, and managers from acute care/trauma and rehabilitation centres. To the best of all knowledge, this was the first study to understand the facilitators and barriers to self-management in SCI and from such multiple perspectives.

Using semi-structured interviews, the following five facilitators to self-management were identified: physical support from the caregiver, emotional support from the caregiver, peer
support and feedback, importance of positive outlook and acceptance, and maintaining independence/control over care. The following five barriers to self-management were identified: caregiver burnout, funding and funding policies, lack of accessibility, physical limitations and secondary complications, and difficulties achieving positive outlook or mood. Overall, this study demonstrated that the caregiver, peer support, perceived control and self-efficacy, mood, and accessibility and funding policies make significant contributions to the self-management of individuals with traumatic SCI. The issues of timing/readiness and comorbidities and aging were observed across many of these themes. It was concluded that the development of a tailored self-management program for individuals with traumatic SCI and their caregivers should incorporate these considerations.

7.1.2 Study Two

The objective of the second qualitative study was to understand the meaning of self-management in traumatic SCI again from the perspectives of individuals with traumatic SCI and their (mainly) spousal caregivers as well as acute care/trauma and rehabilitation managers. To the best of all knowledge, this was the first study to understand the meaning of self-management in SCI from such multiple perspectives, and indeed one of only a few studies that includes a consumer perspective (i.e., patient and caregivers) on the meaning of self-management. The meaning of self-management was related to two overarching themes of internal responsibility attribution and external responsibility attribution. Specifically, the sub-themes of wellness awareness, monitoring for secondary complications, independence-dependence conflict, self-management as an unknown term, directing someone else to provide your care, and ownership of your own care/empowerment in managing your own care comprised internal responsibility attribution. The sub-themes of established chronic disease self-management programs and the
importance of caregiver skill set comprised external responsibility attribution. A clear delineation in the meaning of self-management was noted by the traumatic SCI and caregiver participants (i.e., the SCI-caregiver dyad) versus the manager participants.

7.1.3 Study Three

A survey was developed to further explore the themes identified in the first two studies. The specific content of the survey itself was based on the themes that emerged in the first phase of this study on the facilitators and barriers to and the meaning of self-management in traumatic SCI (i.e., influence of positive/negative mood, self-efficacy) as well as the relevant psychological elements (i.e., module on depression)/underlying theory of the CDSMP (i.e., social cognitive theory and self-efficacy). Thus, the objective of this first quantitative study (i.e., third study) was to determine the relevant components of a self-management program for individuals with traumatic SCI. The components of a self-management program that were rated as “very important” by the greatest proportion of participants included: exercise (n=53; 53.5%), nutrition (n=51; 51.5%), pain management (n=44; 44.4%), information/education on aging with a SCI (n=42; 42.4%), communicating with health care professionals (n=40; 40.4%), problem solving (n=40; 40.4%), transitioning from rehabilitation to the community (n=40; 40.4%), and confidence (in reducing secondary complications/promoting wellness) (n=40; 40.4%). Thirteen percent of participants in the highest activation (i.e., self-management) group had a depression score consistent with a clinically depressed mood. Overall, 74.7% (n=74) of the sample rated the overall importance of the development of a self-management program for individuals with traumatic SCI as “very important” or “important”. Almost 40% (n=39) of the sample indicated a preference for an internet-based self-management program. The highest proportion of participants indicated a preference for having individuals with a similar level of injury (n=74;
a preference for having individuals of a similar age (n=40; 40.4%) was also noted. The importance assigned to the modules on exercise and nutrition was consistent with the qualitative research (i.e., study two on the meaning of self-management) and a wellness/health promotion approach for self-management in this population.

7.1.4 Study Four

Given the emerging importance of depression (i.e., mood) in self-management (i.e., positive/negative mood as a facilitator/barrier to self-management (study one) and the fact that 13% of the participants in the highest activation (i.e., self-management) group had a depression score consistent with a clinically depressed mood (study 3), the second quantitative study aimed specifically, to explore this complexity and further identify the psychological characteristics relevant to self-management that might be associated with depression. A logistic regression determined that lower self-efficacy and mastery scores, as well as less time since injury were associated with depression ($P=0.002; P=0.024, P=0.02$ respectively). Individuals with higher anxiety scores were almost 1.5 times more likely to be depressed, while older age was associated with depression ($P=0.016, P=0.024$ respectively). It was concluded that interventions for depression in SCI including (a) self-management program/training should target factors such as self-efficacy and mastery, which in turn, could improve secondary medical complications and overall quality of life.

7.2 Synthesis of the Two Phases of the Thesis

The results from Phase I and Phase II have been combined in Table 7.1 and Figure 7.1 in order to provide a comprehensive picture of the implementation considerations for a self-management program for individuals with traumatic SCI.
Table 7.1: Synthesis of Results from Phase I and Phase II

<table>
<thead>
<tr>
<th>Self-Management Program Consideration</th>
<th>Results from Phase I Facilitators (F); Barriers (B); Meaning of Self-Management (M)</th>
<th>Results from Phase II</th>
<th>Combined Summary and Program/Implementation Considerations Based on the Results of Phase I &amp; II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver involvement/needs</td>
<td>-Physical support from the caregiver (F)</td>
<td>-36.4% of participants stated that a module on “communicating with family” was “very important”.</td>
<td>-Given the high physical and emotional contributions and demands of caregivers of individuals with traumatic SCI, support for caregivers is warranted. This support for the caregiver would be in form of emotional support and ongoing training to prevent/manage the secondary medical complications of individuals with traumatic SCI.</td>
</tr>
<tr>
<td></td>
<td>-Emotional support from the caregiver (F)</td>
<td></td>
<td>-This support needs to be responsive to the evolving needs of individuals with traumatic SCI (i.e., as they age and/or develop chronic conditions) as well as the similar evolving needs of the caregivers (i.e., aging, chronic conditions).</td>
</tr>
<tr>
<td></td>
<td>-Caregiver burnout (B)</td>
<td></td>
<td>-The sustainability of caregiver activities and support required in SCI (i.e., facilitators to self-management) may be affected by aging and/or the chronic health conditions among caregivers themselves.</td>
</tr>
<tr>
<td></td>
<td>-Directing Someone Else to Provide Your Care (M)</td>
<td>-The caregiver perspective was not sought in Phase II.</td>
<td>-Future research should further explore the support needs of caregivers of individuals with SCI.</td>
</tr>
<tr>
<td></td>
<td>-Importance of Caregiver Skill Set (M)</td>
<td></td>
<td>-A program module on “communicating with family” (e.g., directing someone in the provision of your care) and/or including caregivers/family members in a self-management program for individuals with traumatic SCI could serve to reduce some of this burden.</td>
</tr>
</tbody>
</table>
Table 7.1: Synthesis of Results from Phase I and Phase II (Continued)

<table>
<thead>
<tr>
<th>Self-Management Program Consideration</th>
<th>Results from Phase I</th>
<th>Results from Phase II</th>
<th>Combined Summary and Program/Implementation Considerations Based on the Results of Phase I &amp; II</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Facilitators (F); Barriers (B); Meaning of Self-Management (M)</td>
<td>-Peer support and feedback (F)</td>
<td>-In terms of program make-up, almost 75% of participants indicated that having individuals with a similar level of injury was important. A preference for a program composed of individuals of a similar age was also noted.</td>
</tr>
<tr>
<td>-Peer support and feedback {Peer Leader}</td>
<td>-Matching peer mentors {peer leaders} and mentees {program participants} by specific demographic and clinical/injury characteristics (age, sex, etiology of injury) should be considered.</td>
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<td></td>
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<tr>
<td>Timing</td>
<td>-Timing of support should be considered (e.g., acute phase of recovery may be too early).</td>
<td>-In terms of program timing, 71.7% of the sample would prefer to have a self-management program at the rehabilitation and/or at the transition from rehabilitation to the community period.</td>
<td>-A self-management program could be introduced at the rehabilitation and/or at the transition from rehabilitation to the community period. The introduction of a program before this point may be considered too early (i.e., individuals with traumatic SCI may not be ready to accept the program). However, earlier intervention for depression may be necessary (see Positive/negative mood (i.e., depression) below).</td>
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<tr>
<td></td>
<td></td>
<td>-40.4% of the sample indicated they desired a module on transitioning from rehabilitation to the community.</td>
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</table>
Table 7.1: Synthesis of Results from Phase I and Phase II (Continued)

<table>
<thead>
<tr>
<th>Self-Management Program Consideration</th>
<th>Results from Phase I [QUAL] Facilitators (F); Barriers (B); Meaning of Self-Management (M)</th>
<th>Results from Phase II [quan]</th>
<th>Combined Summary and Program/Implementation Considerations Based on the Results of Phase I &amp; II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independence/ Self-efficacy</td>
<td>-Maintaining Independence/Control over Care (F)</td>
<td>-40.4% of the sample indicated they desired a module on confidence (in reducing secondary complications/promoting wellness).</td>
<td>-A module on promoting confidence/self-efficacy should be considered as part of a self-management program to impact on depression, and potentially, (other) secondary medical complications.</td>
</tr>
<tr>
<td></td>
<td>-Independence/Dependence Conflict (M)</td>
<td>-Self-efficacy was a predictor of depression (OR=.908; p=.002).</td>
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<td></td>
<td>-Ownership of Your Own Care (M)</td>
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</tr>
<tr>
<td>Positive/negative mood (i.e., depression)</td>
<td>-Importance of Positive Outlook and Acceptance (F)</td>
<td>-11% of the sample reported that they had visited their family physician in the past 12 months for depression. However, among this group with a family physician, 25.5% of the sample had a depression score consistent with a clinically depressed mood.</td>
<td>-A self-management program for individuals with traumatic SCI should include/address the following modules in order to address depression:</td>
</tr>
<tr>
<td></td>
<td>-Difficulty Achieving Positive Outlook or Mood (B)</td>
<td>-Lower self-efficacy (OR=.908; p=.002), lower mastery (OR=.718; p=.024), higher anxiety (OR=1.463; p=.016), less time since injury (OR=.915; p=.020), and increasing age (OR=1.084; p=.024) were associated with depression status.</td>
<td>-Increasing confidence (i.e., self-efficacy), increasing mastery of managing condition</td>
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<td></td>
<td></td>
<td></td>
<td>-Dealing with anxiety</td>
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<td></td>
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<td></td>
<td>-Offer/adopt a module for those with (more) recent time since injury</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>-A module on dealing successfully with aging and associated co-morbidities in SCI could be associated with lower rates of depression.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>-A module on how caregivers can recognize depression should be considered.</td>
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</tbody>
</table>
Table 7.1: Synthesis of Results from Phase I and Phase II (Continued)

<table>
<thead>
<tr>
<th>Self-Management Program Consideration</th>
<th>Results from Phase I [QUAL] Facilitators (F); Barriers (B); Meaning of Self-Management (M)</th>
<th>Results from Phase II [quan]</th>
<th>Combined Summary and Program/Implementation Considerations Based on the Results of Phase I &amp; II</th>
</tr>
</thead>
</table>
| Secondary complications              | -Physical Limitations and Secondary Complications (B)  
- Monitoring for Secondary Complications (M)  
- Wellness Awareness (M)                  | The components of a self-management program [that address secondary complications] that were rated as “very important” by the greatest proportion of participants included: exercise (53.5%), nutrition (51.5%), pain management (44.4%), information/education on aging with a SCI (42.4%), and communicating with health care professionals (40.4%).  
- The most common reasons for a family physician visit in the past 12 months was for bladder dysfunction (e.g., urinary tract infection) (47.9%), followed by pain (37.2%), bowel issues (20.2%). 18.2% had visited the emergency department in the past 12 months for injury. | -The following modules in a self-management program for individuals with traumatic SCI are suggested (results reflect some of the above findings from caregiver involvement/needs, independence/self-efficacy, positive/negative mood):  
- Wellness/health promotion components:  
  -- Exercise  
  -- Nutrition  
  -- Information/education on aging with a SCI  
- Pain management  
- Bladder care  
- Bowel care  
- (Preventing) injury  
- Dealing with depression  
  -- Increasing confidence (i.e., self-efficacy) in managing condition.  
  -- Increasing mastery of managing condition  
- Dealing with anxiety  
- Communicating with health care professionals (especially about low mood/depression)  
- Communicating with family (e.g., directing someone in the provision of your care) |
<table>
<thead>
<tr>
<th>Self-Management Program Consideration</th>
<th>Results from Phase I [QUAL] Facilitators (F); Barriers (B); Meaning of Self-Management (M)</th>
<th>Results from Phase II [quan]</th>
<th>Combined Summary and Program/Implementation Considerations Based on the Results of Phase I &amp; II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessibility</td>
<td>-Funding and Funding Policies (B) -Lack of accessibility (B)</td>
<td>-In terms of modes of delivery, 39.4% of the sample indicated a preference for an internet-based self-management program.</td>
<td>-The delivery of a self-management program for individuals with traumatic SCI should address barriers with respect to accessibility and consider the use an internet-based program. Additional promotion of awareness/knowledge of various funding programs and advocacy skills training would be beneficial.</td>
</tr>
</tbody>
</table>
### Figure 7.1: Proposed Self-Management Program for Individuals with Traumatic SCI

<table>
<thead>
<tr>
<th>Organization, Timing, and Follow-up:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Organized by a community-based organization such as SCI Canada during the rehabilitation-transition from rehabilitation to community period (depression may need to be addressed earlier and booster sessions may be required for older adults with SCI to reduce the risk of depression), with regular contact with (an) individual(s) from the group for follow-up.</td>
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<tr>
<th>Mode of Delivery:</th>
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<tbody>
<tr>
<td>- Delivered via the internet to minimize barriers with respect to accessibility.</td>
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</table>

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<tr>
<th>Format, Program Leaders:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- One-on-one format.</td>
</tr>
<tr>
<td>- Health care professional (potentially to address secondary medical complications) and peer leader (potentially to address the emotional complexities of SCI; peer leaders should have a similar level of injury, be of similar age).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Modules (Content) (Overall Wellness/Health Promotion Approach)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Wellness/health promotion components:</td>
</tr>
<tr>
<td>-- Exercise</td>
</tr>
<tr>
<td>-- Nutrition</td>
</tr>
<tr>
<td>-- Information/education on aging with a SCI (e.g., wellness approaches for successful aging/reducing risk of co-morbidities, including heart disease).</td>
</tr>
<tr>
<td>- Pain management</td>
</tr>
<tr>
<td>- Bladder care</td>
</tr>
<tr>
<td>- Bowel care</td>
</tr>
<tr>
<td>- (Preventing) injury</td>
</tr>
<tr>
<td>- Information/education on sexuality and SCI</td>
</tr>
<tr>
<td>- Dealing with depression</td>
</tr>
<tr>
<td>-- Increasing confidence (i.e., self-efficacy) in managing condition</td>
</tr>
<tr>
<td>-- Increasing mastery of managing condition.</td>
</tr>
<tr>
<td>-- Dealing with anxiety</td>
</tr>
<tr>
<td>-- Communicating with health care professionals (especially about low mood/depression)</td>
</tr>
<tr>
<td>-- Improving the outcomes (modules) related to depression and depression itself may in turn increase patient activation/self-management and reduce secondary medical complications.</td>
</tr>
<tr>
<td>- Communicating with family (e.g., directing someone in the provision of your care)</td>
</tr>
</tbody>
</table>

### 7.3 Strengths and Limitations

#### 7.3.1 Strengths

Collectively, this research has several methodological strengths. The sequential exploratory design is considered the ideal approach for exploring a phenomenon that has been
previously unexplored (Creswell et al., 2003) and is considered particularly useful for the
development of an intervention (Kroll & Morris, 2009). Both of these scenarios were relevant to
the current research. Furthermore, the in-depth study of self-management in this population
(perceived facilitators and barriers, meaning, preferences, and an important and specific barrier
to self-management, depression), will allow for the development of a detailed and appropriate
program that is responsive to the needs of this population versus implementing a resource-
intensive randomized controlled trial using an existing self-management program that has not
been tailored to the needs of this population. The use of multiple perspectives including
individuals with traumatic SCI, their caregivers, and health care (or clinical) managers in the
qualitative phase specifically provided the opportunity to compare and contrast their findings,
yielding a comprehensive “story” of the self-management needs of/considerations for individuals
with traumatic SCI (Kroll & Morris, 2009). It is believed that this iterative process as well as the
involvement of multiple stakeholders from across the province (in the first phase of the study)
has enhanced the utility, relevance, trustworthiness (i.e., internal validity), and applicability (i.e.,
external validity) of the findings.

With respect to the quantitative phase, several strengths were also noted. For example,
the survey used validated or standardized measures, including the MSES, which had been
developed specifically to measure the self-efficacy of individuals with SCI (Middleton et al.,
2003). Despite some of the concerns for a selection bias among the current participants
(discussed below), the use of a nationally-based sample increased the generalizability of the
phase two study findings. In fact, the high degree of concordance between the qualitative and
quantitative data validates the findings in Phase I.
7.3.2 Limitations

As with all research, some limitations in both the qualitative and quantitative phases are acknowledged. For the qualitative phase (i.e., studies one and two), in terms of the recruitment procedure, it is likely that a selection bias operated in those participants who agreed to take part in the research – they may have been healthier and/or had better/more interest in self-management skills than those individuals who chose not to participate. In addition, all participants had to have a caregiver who was willing to participate, increasing the likelihood that healthier individuals with SCI participated in the qualitative phase. The majority of traumatic SCI participants in the current study were male, which is consistent with the epidemiology of population-based studies (e.g., Couris et al., 2010), with female caregivers. Thus, it is unknown whether the findings from the qualitative phase can be applied to females with traumatic SCI and their caregivers. Collectively, these factors may have limited the applicability of the results. However, if the current sample for the qualitative phase was indeed healthier than the general population of individuals with traumatic SCI it could be argued that the appropriate input was obtained for the development of a self-management intervention for individuals with traumatic SCI and their caregivers as a certain level of intrinsic motivation and support is required in order to successfully participate in a self-management program (Bandura, 2004; Kehn & Kroll, 2009; Kooijmans et al., 2013).

For the quantitative phase (i.e., studies three and four), although a national sample was employed, the sample size was relatively small, and it is likely that it was not representative of the broader group of individuals with traumatic SCI. Instead, it is likely that the current sample represented a more engaged and healthier group of individuals with traumatic SCI (e.g., 95% of the sample reported having a family physician; 62.6% were in the “maintaining behaviours”
segment of self-management/activation), as assumed in the qualitative phase. However, given that three-quarters of this (relatively healthy) sample believed that the development of a self-management program was “important” or “very important”, it is likely the development of a self-management program in this population is even more warranted among those individuals who are not as high-functioning. In addition, the design of phase two of the thesis was cross-sectional and therefore it is unknown how the reported perspectives on the components of a self-management program change over time/vary by various stages of the recovery trajectory. This design also precludes the ability to establish causal links between depression and the psychological characteristics of interest. The reliance on self-report measures of psychological outcome are considered to be subjective, and thus presented a testing bias. Lastly, given the distribution of the patient activation scores found in studies three and four (i.e., inconsistent with a normally distributed population), it is possible that the existing version of the PAM was not a sensitive enough measure of patient activation in a SCI population.

7.4 Suggestions for Future Research in Self-Management and Spinal Cord Injury

This thesis highlighted many areas of future research; however, the following key areas are described below:

1. The further examination of the complexity/mechanisms of the relationships and inter-relationships between mood (i.e., depression), self-efficacy, patient activation/self-management, and secondary complications in SCI as well as other factors, such as time since injury, is necessary. This could be accomplished via more complex statistical modeling including structural equation modeling.

2. Across several domains including peer support, perceived control and self-efficacy, and mood, the issue of timing/readiness was raised. Future, longitudinal research is needed to examine how
these factors evolve over time (and under what conditions/circumstances, with which characteristics?) In particular, future research should examine if/how patient activation evolves over time. With this knowledge, corresponding (self-management) interventions could be modified depending on if/how these various factors change over time. Furthermore, as individuals with SCI are living longer, these issues may be complicated by co-morbid chronic conditions. Thus, the role of aging and comorbidity in SCI, in general, and as they relate to these issues, warrants further research.

3. Overall, more research is needed to examine the barriers to (mental health) care that may be contributing to the low rates of depression treatment in SCI as well as systematically study treatments for depression (e.g., psychological interventions, antidepressants) after SCI.

4. Future research should investigate the relevance of the PAM in a SCI population. The development of patient activation/self-management measures specific to SCI may be necessary. At a minimum, the use/development of a modified PAM that might better distinguish between levels of readiness for effective self-management among individuals with (traumatic) SCI, specifically, should be investigated.

5. Future research could also determine a more comprehensive list of mentor/mentee (or program peer leader/program participant) characteristics and what specific characteristics or combination of characteristics are tied with increased self-management among individuals with traumatic SCI. Future research could also determine the appropriate levels of mentorship/support at varying stages of recovery in order to optimize moderating/mediating variables or outcomes of self-management (e.g., increased self-efficacy, decreased number of secondary conditions).
6. With larger sample sizes, it is suggested that future research investigate preferred modules/content as well as other components of a self-management program by various demographic and clinical variables including age, sex, time since injury, and level of injury.

7. Using the self-management program components suggested in this thesis, future research should involve the actual development, pilot-testing, evaluation, and implementation of a targeted self-management program for individuals with (traumatic) SCI (i.e., in accordance with the phases of the new Medical Research Council framework for the design and evaluation of complex interventions to improve health (Campbell et al., 2000; Craig et al., 2008). For example, once this program has been pilot-tested, subsequent research should involve a randomized controlled trial to test the effectiveness of this proposed program in reducing secondary complications (i.e., physical, psychological). These next phases could be conducted either locally (in Ontario or other Canadian provinces) or internationally. Part of this future research would involve the exploration of what the ideal outcomes of a self-management program in SCI are (i.e., what are the other meaningful outcomes beyond reducing secondary medical complications that should be considered?)

8. Future research could also replicate all or some of the studies in other sociocultural settings/contexts (e.g., in other countries where the definition of self-care/self-management might differ) to validate the study findings and/or adapt the considerations to specific contexts. These findings could then be used to formulate a self-management program for individuals with traumatic SCI in these other contexts, and potentially, assess their impact.

9. Further research is required in the area of interventions to promote caregiver well-being especially given caregivers’ critical role to the individual with traumatic SCI and the health care system as a whole. While previous research has focused on the area of physical support or
activities of daily living, further research is required on the emotional support that caregivers provide to individuals with traumatic SCI and the associated patient outcomes. The issue of aging and/or chronic health conditions among caregivers as a threat to the sustainability of caregiving activities was also raised, especially given the extent of support required in SCI. Future research and/or interventions should address these important considerations.

10. Lastly, future research may examine the generalizability/comparability of the current findings to other chronic disease populations. The current research is one of only a few studies to include a consumer prospective (i.e., patient, caregiver) on the meaning of self-management. Given that much of the chronic illness self-management literature is from the perspective of health care professionals (e.g., Lorig et al., 1998; Barlow et al., 2000), a greater understanding of the meaning of self-management from the patient perspective in other chronic conditions is required in order to better tailor self-management support to the individuals (and their caregivers).

7.5 Implications for Knowledge Translation/Implementation Science

Collectively, and consistent with the phases of the new Medical Research Council framework for the design and evaluation of complex interventions to improve health (Campbell et al., 2000; Craig et al., 2008), the findings from this research could be used to develop, pilot test, evaluate, and implement a self-management program for individuals with traumatic SCI. Similarly, using the KTA framework, this thesis focused on the phases of 1) identifying the problem (i.e., understanding the meaning of self-management in traumatic SCI (Paper 2) and the need for a self-management program that is responsive to the needs of individuals with SCI); 2) adapting the knowledge use (i.e., Papers 3 and 4); and, 3) assessing the facilitators and barriers to knowledge use (i.e., Paper 1). Collectively, the findings from Phases I and II could be used for
the development of a tailored self-management program (see Figure 7.2). Other phases of KTA cycle could be the focus of future research including the phases of implementing and evaluating the intervention (as previously suggested by the MRC framework), and sustaining ongoing knowledge use.

Figure 7.2 Adapted Knowledge-to-Action Framework (Adapted from Graham et al., 2006)

7.6 Clinical Implications

Indeed, the implementation of such a program could serve to fill the existing gaps in the health care system. For example, and as previously discussed, the trend of decreasing length of
stay in rehabilitation facilities has led to individuals with SCI entering the community with fewer self-care skills to prevent secondary complications (Chen et al., 1999; McColl et al., 2012). Families and others comprising the informal support network also have less time to adjust. Thus, the current program could augment the self-care/self-management skills of individuals with traumatic SCI as well as begin to support caregivers/family members in assisting the individual with traumatic SCI with his or her self-management. However, given the significant physical and emotional contributions of caregivers/family members to individuals traumatic SCI, as well as the identified caregiver burden, a self-management program for individuals with SCI must involve some concurrent (psychological) support for caregivers. Two recent studies of interventions to assist family caregivers demonstrated promise in reducing the impact of this burden (Elliott & Berry, 2009; Schulz et al., 2009), and in doing so, may promote ongoing care and/or sustainability of the care provided to individuals with traumatic SCI. For example, Elliott and Berry (2009) demonstrated that an intervention for the family members of individuals with recent onset SCI, comprising problem solving, education, and telephone contact, had beneficial effects on caregiver problem-solving styles as well as social and physical functioning. The findings of Schulz and colleagues (2009) support the development and implementation of self-management interventions with a dual-target approach (i.e., the inclusion of individuals with SCI as well as their caregivers) that specifically acknowledge the interactive nature of caregiver and care recipient outcomes. Participants also raised the issue of aging and/or chronic health conditions among caregivers as a threat to the sustainability of caregiving activities, especially given the extent of support required in SCI.

The current research also underscored a care gap in the area depression and SCI and, given the importance of positive/negative mood as both a facilitator and barrier to self-
management, a need to focus on depression in (a) self-management program/training. Overall, more research is needed to examine the barriers to care that may be contributing to the low rates of depression treatment in SCI as well as systematically study treatments for depression (e.g., antidepressants) after SCI (Fann et al., 2011). In Study Three, 11% (n=10) of the sample reported that they had visited their family physician in the past 12 months for depression. However, among this group with a family physician, 25.5% of the sample (n=24) had a depression score consistent with a clinically depressed mood. It is unknown whether this result is due to the individual with traumatic SCI’s fear/lack of confidence in bringing up this topic with his/her physician (i.e., stigma), the prioritization of ongoing, complex medical concerns of individuals with SCI versus emotional concerns of individuals with SCI (Fann et al., 2011), and/or family physicians’ lack of knowledge in dealing with individuals with SCI. As previously mentioned, primary health care professionals rarely have patients with SCI in their practice (although depression is not unique to SCI). Consequently, they do not often have much opportunity to gain sufficient knowledge and experience about the specific care these patients need (Bloemen-Vrencken et al., 2005). In order to support individuals with SCI and their self-management efforts (e.g., dealing with depression), family physicians must engage in early/ongoing education on SCI (e.g., learn to ask their SCI patients about their mood and its impact on preventing other secondary medical complications). It also highlights the need for patients and/or their caregivers to actively engage in their care. These issues relate to the findings of Guilcher and colleagues (2013) on the journey of care of individuals with SCI in the prevention of management of secondary conditions. They determined that unless health system barriers, including formal care providers’ lack of knowledge regarding SCI and its associated
secondary conditions, are removed/diminished, efforts to promote (a) self-management program/training will be challenged.

As previously outlined, the current research is one of only a few studies to include a patient prospective on the meaning of self-management. Much of the chronic illness self-management literature is from the perspective of health care professionals (e.g., Lorig et al., 1998; Barlow et al., 2000); thus, the current research and future studies that take the patient perspective into account have the potential to change existing/accepted self-management programs. Moreover, a growing body of literature indicates that adapting evidence-based self-management programs (i.e., the suggested modules were informed by the CDSMP) for use by specific groups can improve their reach and possibly their effectiveness (Backer, 2002; Wandersman, 2003; Devieux et al., 2005; Pemberton et al., 2009). Evidence-based programs are most often adapted when the target population for the intervention differs with respect to risk behaviours or age composition from the population in which the program’s effectiveness was established. This planned adaptation can balance fidelity to the program’s core components while optimizing its fit for the new target population (Casto et al., 2004). Indeed, the RHI has recognized the value of this patient perspective and associated planned adaptation. It has identified the need for a pilot, patient self-management program, developed and implemented in partnership with individuals with SCI as well clinicians and consumer organizations, as one of its strategic directions for 2013-2018.

7.7 End of Thesis Knowledge Translation Plan

An appropriate knowledge translation strategy will be implemented at the conclusion of the thesis using both passive and active/action-oriented strategies. The messages will be clear, simple, and tailored to the unique needs of each target end user, whether these are individuals or
organizations (including their preferences for receiving this information). For example, the results will be presented at relevant meetings locally, nationally (Canadian Association for Health Services and Policy Research conference), and internationally (International Spinal Cord Society conference) and published in peer-reviewed journals (e.g., BMC Neurology, Disability and Rehabilitation) so that results are available to the appropriate academic and clinical audiences. Ideally, all relevant stakeholders (e.g., investigators, collaborators, knowledge users) will be convened to 1) identify key messages relevant to each stakeholder group; 2) determine the main target audiences for each of these messages and the associated messengers; 3) identify barriers to uptake; and, 4) discuss strategies to ensure the sustainability of the research findings. For example, key messages tailored to consumers and researchers could be disseminated through the newsletters (print and on-line) of interested organizations, such as the Ontario Neurotrauma Foundation and SCI Canada. Since participants were mainly recruited through the RHI for Phase II of the study, results of the survey, specifically, could be disseminated via a RHI newsletter. Partnerships have been made with the RHI and associated researchers to continue this research by pilot testing a program based in part on the considerations outlined in this thesis.

7.8 Conclusion

These four studies contribute to a greater understanding of self-management in individuals with traumatic SCI, the perceived facilitators and barriers to self-management in this population, and the preferred implementations considerations (i.e., components/modules, modes of delivery, format, etc.) for a targeted self-management program for individuals with SCI. The importance of positive/negative mood (i.e., depression) was highlighted in self-management, and the psychological characteristics (i.e., self-efficacy, mastery, patient activation) in self-management that are associated with depression in individuals with a traumatic SCI were
identified. Future research is needed for the development of training and (psychological) interventions to provide ongoing support to the caregivers of individuals with traumatic who contribute significantly to/sustain the self-management of the individual with traumatic SCI. These interventions could be integrated into the proposed self-management program for individuals with traumatic SCI or delivered separately. Collectively, these findings could be used for the development, pilot-testing, and evaluation of a targeted self-management program. It is anticipated that such a program could have a significant impact on reducing secondary complications in SCI, attenuating caregiver burnout, and enhancing quality of life for individuals with SCI.
CANDIDATE’S ROLE

The candidate (SEPM) conceived the research objectives addressed in this thesis, developed the study protocol with contributions from thesis committee members (Dr. Susan Jaglal, Dr. Sharon Straus, Dr. Michael Fehlings, Dr. Eunice Jang, and Dr. Fiona Webster), recruited the participants/liaised with the Rick Hansen Institute and Toronto Western Hospital to recruit the participants, conducted all interviews, performed all the data analysis, and wrote the thesis manuscript.
References

[Chapters 1 and 2]


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[Chapter 3]


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[Chapter 4]


NVivo qualitative data analysis software; QSR International Pty Ltd. Version 9, 2010.


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[Chapter 5]


Munce SEP, Webster F, Fehlings MG, Straus SE, Jang E, Jaglal SB. Perceived Facilitators and Barriers to Self-Management in Individuals with Traumatic Spinal Cord Injury: A Qualitative Descriptive Study. BMC Neurol (Accepted March 2014).


Rick Hansen Institute [http://www.rickhanseninstitute.org/]


[Chapter 6]


Rick Hansen Institute [http://www.rickhanseninstitute.org/]


[Chapter 7]


Appendix A

Chapters 3 and 4: Research Ethics Board Approval Letter
(Phase I)

PROTOCOL REFERENCE # 26429

June 16, 2011

Dr. Susan Brenda Jaglal
Physical Therapy
University of Toronto
160-500 University Ave.
Toronto, ON M5G 1V7

Ms. Sarah Elizabeth Patricia Munce
Physical Therapy
University of Toronto
160-500 University Ave.
Toronto, ON M5G 1V7

Dear Dr. Jaglal and Ms. Munce:


ETHICS APPROVAL Original Approval Date: June 16, 2011

Expiry Date: June 15, 2012

Continuing Review Level: 1
We are writing to advise you that the Health Sciences Research Ethics Board has granted approval to the above-named research study under the REB’s delegated review process. Your study has been approved for a period of one year and ongoing projects must be renewed prior to the expiry date.

All your most recently submitted documents have been approved for use in this study.

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

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your study. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry, as per federal and international policies.

If your research has funding attached, please contact the relevant Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your project.

Yours sincerely,
Dario Kuzmanovic
Research Ethics Analyst
STUDY ON SELF-CARE BEHAVIOURS OF INDIVIDUALS AND THEIR CAREGIVERS/FAMILIES WITH TRAUMATIC SPINAL CORD INJURY

RESEARCH PARTICIPANTS NEEDED!

We are looking for individuals with spinal cord injury who

- Sustained their injury because of a traumatic cause (i.e., a fall, motor vehicle collision, sporting accident, etc)
- Are 18 years of age or older
- Are English-speaking
- Have a family member/caregiver who is willing to speak with us

I am graduate student from the University of Toronto completing my PhD in the Department of Health Policy, Management & Evaluation.

The purpose of this study is to understand your current self-management or self-care behaviours as well as the role of your family member or caregiver in these self-care behaviours. We are also interested in those factors that make it easier or harder to carry out these self-care behaviours.

Participants will be required to:

- Take part in a telephone interview that lasts approximately 60 minutes.

This research has received ethics clearance from the University of Toronto’s Research Ethics Board (Protocol Reference #26429).

If you are interested in learning more about the study, please contact Sarah Munce toll-free at 1-855-946-7902, or email sarah.munce@utoronto.ca
Title: Considerations for Self-Management Support to Reduce Secondary Complications for Individuals with Traumatic Spinal Cord Injury

Investigator: Sarah Munce, MSc, PhD Candidate, Department of Health Policy, Management & Evaluation; 500 University Avenue Rm. 851, Toronto, Ontario, Canada M5G 1V7; 416-946-7902; sarah.munce@utoronto.ca

You are being asked to take part in a research study. Before agreeing to participate in this study, it is important that you understand the following explanation of the proposed study procedures. The following information describes the purpose of the research, eligibility, procedures, and risks and benefits associated with this study. You have the right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask the Investigator (Sarah Munce) to explain any words you don’t understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before agreeing to participate in this study.

Background and Purpose of Research: You have been asked to participate in an interview to understand your current self-management or self-care behaviours as well as the role of your family member or caregiver in these self-care behaviours. We are also interested in those factors that make it easier or harder to carry out these self-care behaviours. This project is being carried out as part of the doctoral (PhD) work of Sarah Munce (the “Investigator”) and represents the first of two phases of the study. We will be speaking with approximately 24 individuals with spinal cord injury and their family members. We will also be speaking with approximately eight health care professionals who treat individuals with spinal cord injury, such as yourself/your family member. We will be speaking with individuals across the province.

Eligibility: To participate in this study you must have a traumatic spinal cord injury (i.e., sustained from a fall, motor vehicle collision, sporting accident, etc), be greater than 18 years of age and English-speaking.

The family member/caregiver will be identified by the person with the spinal cord injury.
**Procedures:** You are asked to participate in a telephone interview lasting approximately 60 minutes. The interview for your family member may also last 60 minutes. As stated above, you and your family member/caregiver will be asked about your current self-management or self-care behaviours as well as the role of your family member or caregiver in these self-care behaviours. We are also interested in those factors that make it easier or harder to carry out these self-care behaviours.

**Risks:** There are no risks associated with participation in the interview.

**Benefits:** Information gathered from the interview will provide a better understanding of the current self-management or self-care behaviours as well as those factors that make it easier or harder to carry out these self-care behaviours.

**Privacy & Confidentiality:** All information obtained during the study will be held in strict confidence and stored securely. No names or identifying information will be used in any publication or presentations. The interview will be audio-taped. Investigators will listen to the audio-tapes. Participants will not be identified by name or occupation on the tapes.

**Publication of Research Findings:** Direct quotes from the discussion may be used in reports and/or published articles, but no identifying information will be provided with these quotes or anywhere else in the final report.

**Participation:** Your participation in this study is voluntary. You can choose not to participate or you may withdraw at any time without risk of penalty.

**Rights of Participants:** You waive no legal rights by participating in this study.

**Questions:** If you have any future questions about the study, please contact Sarah Munce, the principal investigator at telephone 416-946-7902 or by email: sarah.munce@utoronto.ca

If you have any questions about your rights as a research participant, please contact Jill Parsons, Health Sciences Ethics Review Officer, Ethics Review Office, University of Toronto at telephone 416-946-5806 or by email: jc.parsons@utoronto.ca

**Consent:** I acknowledge that I have had the opportunity to discuss this study and my questions have been answered to my satisfaction. I consent to take part in the study with the understanding I may withdraw at any time without risk of penalty. I have received a signed copy of this consent form. I voluntarily consent to participate in this study.

Signature:   Printed Name:    Date:

Signature of Family Member:   Printed Name:   Date:
Appendix D

Chapters 3 and 4: Consent Form – Manager Version

[Health Care Professional/Hospital Administrator Version]

Title: Considerations for Self-Management Support to Reduce Secondary Complications for Individuals with Traumatic Spinal Cord Injury

Investigator: Sarah Munce, MSc, PhD Candidate, Department of Health Policy, Management & Evaluation; 500 University Avenue Rm. 851, Toronto, Ontario, Canada M5G 1V7; 416-946-7902; sarah.munce@utoronto.ca

You are being asked to take part in a research study. Before agreeing to participate in this study, it is important that you understand the following explanation of the proposed study procedures. The following information describes the purpose of the research, eligibility, procedures, and risks and benefits associated with this study. You have the right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask the Investigator (Sarah Munce) to explain any words you don’t understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before agreeing to participate in this study.

Background and Purpose of Research: You have been asked to participate in an interview to understand those factors that make it easier or harder to carry out these self-care behaviours for individuals with spinal cord injury. This project is being carried out as part of the doctoral (PhD) work of Sarah Munce (the “Investigator”) and represents the first of two phases of the study. We will be speaking with approximately 24 individuals with spinal cord injury and their family members. We will also be speaking with approximately eight health care professionals, who treat individuals with spinal cord injury, such as yourself. We will be speaking with individuals across the province.

Procedures: You are asked to participate in a telephone interview lasting approximately 60 minutes. As stated above, you will be asked about those factors that make it easier or harder to carry out self-care behaviours in individuals with spinal cord injury.

Risks: There are no risks associated with participation in the interview.

Benefits: Information gathered from the interview will provide a better understanding of those factors that make it easier or harder to carry out these self-care behaviours in individuals with spinal cord injury.
Privacy & Confidentiality: All information obtained during the study will be held in strict confidence and stored securely. No names or identifying information will be used in any publication or presentations. The interview will be audio-taped. Investigators will listen to the audio-tapes. Participants will not be identified by name or specific occupation on the tapes.

Publication of Research Findings: Direct quotes from the discussion may be used in reports and/or published articles, but no identifying information will be provided with these quotes or anywhere else in the final report.

Participation: Your participation in this study is voluntary. You can choose not to participate or you may withdraw at any time without risk of penalty.

Rights of Participants: You waive no legal rights by participating this study.

Questions: If you have any future questions about the study, please contact Sarah Munce, the principal investigator at telephone 416-946-7902 or by email: sarah.munce@utoronto.ca

If you have any questions about your rights as a research participant, please contact Jill Parsons, Health Sciences Ethics Review Officer, Ethics Review Office, University of Toronto at telephone 416-946-5806 or by email: jc.parsons@utoronto.ca

Consent: I acknowledge that I have had the opportunity to discuss this study and my questions have been answered to my satisfaction. I consent to take part in the study with the understanding I may withdraw at any time without risk of penalty. I have received a signed copy of this consent form. I voluntarily consent to participate in this study.

Signature: Printed Name: Date:
Interview Guide for Individuals with Traumatic Spinal Cord Injury

A. Background Information

Date of Interview:

Time of Interview:

Thank individual for participating, go over consent form and have them verbally agree to participate, explain process, how confidentiality and anonymity will be protected, etc.

Underscore the fact that we are having a conversation; it is his or her experiences and input that are important. Underscore that they don’t have to answer any questions that they are uncomfortable answering.

B. Warm-up and Establishing Rapport

- It would be nice if you could let me know a little about yourself [this information may have been obtained ahead of time]:
  - How the injury occurred (mechanism of injury) and when he or she sustained his or her injury
  - Level of injury
  - Age
  - Race/ethnicity
  - Marital status
  - Number of children
  - Living situation
  - Dwelling status i.e., house or apartment?
• Rural/urban status
• Education: less than high school, high school, undergraduate, postgraduate.
• Employment status
• Individual and family income: <$20,000, $20-40K, $40-60K, $60-80K, $80-100K, $100K+
• Insurance Status

C. Current Self-management Strategies [In your experience…]

1. Walk me through what you are currently doing to manage your condition?

2. How do you know you’re doing ok; that you can carry on your daily activities; are you satisfied with how you’re performing your daily activities?

3. What is self-management from your perspective (what comes to mind when you hear the phrase self-management), that is, what sort of strategies or activities do you do to keep yourself healthy [Probes: examples of self-management – changing dressings (medically-based), communicating with physicians (skill-based), seek social support]? Probe: What is the ultimate goal of self-management?

Secondary Complications

1. What are you currently doing to prevent any secondary complications, that is, any medical conditions that arise as a result of your spinal cord injury, such as urinary tract infections or pressure ulcers?
Health Care Utilization

1. What prompted your last visit to hospital or your physician’s office? Probes: What was that experience like? Were you comfortable talking to the physician about your health concerns? Did you feel as if you got the answers to all your questions and/or all of your concerns were addressed?

What kind of specific help did you need after that visit (attendant care, etc.)? Who or what helped you meet these needs? Was there anything that was not helpful?

D. Barriers and Facilitators of Self-Management [can think in terms of helpful/not as helpful]

1. What are some of the factors that have contributed to success in self-management (definition of self-management: self-care activities which promote wellness or activities or strategies that you do to keep yourself healthy and/or manage or prevent secondary complications)?

2. What are some of the factors that have impeded success in ability to maintain self-management (definition of self-management: self-care activities which promote wellness or activities or strategies that you do to keep yourself healthy and/or manage or prevent secondary complications)?

E. CDSMP

- Describe the Stanford CDSMP and its modules and the fact that it is based on social cognitive learning theory (self-efficacy, outcome expectancy) – what are the advantages and disadvantages of this approach in a spinal cord injury population/what is helpful not as helpful about this program to individuals with spinal cord injury?

Description of Self-Management Program:

The Stanford Chronic Disease Self-Management Program (CDSMP) is one of the most widely used self-management programs (Lorig et al., 1999; 2001). The Stanford CDSMP seeks to provide patients with the confidence and skills to better manage their chronic medical conditions, regardless of specific diagnosis (Lorig et al., 1999a; 2001). Individuals (non-health care professionals) who deliver the program are given a great deal of training so that the
program is delivered in a consistent manner. For example, people with personal experience with one or more chronic conditions must successfully complete an intensive and standardized 4.5-day long training program to become facilitators or lay leaders certified to provide the CDSMP. Pairs of certified facilitators deliver the intervention with the use of a Leaders’ manual (i.e., to ensure consistency of content) to groups of 8-10 participants over 6 weekly sessions. Each session lasts approximately 2 hours, and is delivered in community settings (e.g., church halls).

The CDSMP covers generic topics including: an overview of self-management principles, exercise, pain and fatigue management, relaxation techniques (e.g., guided imagery and breathing exercises), dealing with depression, nutrition, communicating with family and health professionals, problem solving, and goal setting. Goals should be achieved during the following week, be personally relevant, achievable, challenging, have definite outcomes, and depend largely upon a person’s own efforts. Participants report back to the group on their achievements at the next weekly session. The format of the course is largely participatory and interactive, with short ‘lecturettes’ to introduce topics, group discussion, problem solving, role plays, and mastery experience (i.e., trying out the skills introduced on the course). Participants are encouraged to apply these generic skills to their own situation. Specifically, participants are taught to use behaviour change ‘action plans’, to use an organized approach to solving common self-management problems, and are given lots of opportunities to practice these skills and receive feedback on their performance (Jerant et al., 2005).
F. Wrap-up Questions

- Is there anything else I haven’t asked you about that you’d like to add/are there any questions that I can answer?

- The responses you have provided may stimulate some additional questions or need for further clarification. If so, may we contact you in the future? *Explain rest of process (e.g., that the results of the studies will be shared with participants…)*
Interview Guide for Primary Caregiver: Family Members/Caregivers/Attendants of Individuals with Traumatic Spinal Cord Injury

A. Background Information

Thank individual for participating, go over consent form and have them verbally agree to participate, explain process, how confidentiality and anonymity will be protected, etc.

B. Warm-up and Establishing Rapport

- It would be nice if you could let me know a little about yourself. [Need age, gender, relationship to individual with SCI] [this information may have been obtained ahead of time].

C. Current Self-management Strategies

1a. Walk me through what you are currently doing to help manage [insert patient’s name] condition?

1b. Walk me through what you are currently doing to help yourself in the taking care of the patient’s conditions.

2a. How do you know they are doing ok/you’re helping them?

2b. How do you know you’re doing ok?

3a. What is self-management from your perspective (what comes to mind when you hear the phrase self-management), that is, what sort of strategies or activities do you do to keep [insert patient’s name] healthy [Probes: examples of self-management – changing dressings (medically-based), communicating with physicians (skill-based), seek social support]?

Probe: What is the ultimate goal of self-management?

3b. What sort of strategies or activities do you do to keep yourself healthy [Probes: examples of self-management – changing dressings (medically-based), communicating with
Interview Guide for Primary Caregiver: Family Members/Caregivers/Attendants of Individuals with Traumatic Spinal Cord Injury

physicians (skill-based), seek social support]? Probe: What is the ultimate goal of self-management?

Secondary Complications

1. What are you currently doing to help the patient [insert name] prevent any secondary complications, that is, any medical conditions that arise as a result of your spinal cord injury, such as urinary tract infections or pressure ulcers?

Health Care Utilization

1a. What prompted the patient’s [insert patient’s name] last visit to hospital or your physician’s office? Probes: What was that experience like? Were you comfortable talking to the physician about your health concerns? Did you feel as if you got the answers to all your questions and/or all of your concerns were addressed? What kind of help did you need after that visit? Who or what helped you meet these needs? Was there anything that was not helpful?

D. Barriers and Facilitators of Self-Management [can think in terms of helpful/not as helpful]

1a. What are some of the factors that have contributed to success in self-management (of the patient) (definition of self-management: self-care activities which promote wellness or activities or strategies that you do to keep yourself healthy and/or manage or prevent secondary complications)?

1b. What are some of the factors that have contributed to success in your own self-management (definition of self-management: self-care activities which promote wellness or activities or strategies that you do to keep yourself healthy and/or manage or prevent secondary complications)?

2a. What are some of the factors that have impeded success in self-management (of the patient) (definition of self-management: self-care activities which promote wellness or activities or strategies that you do to keep yourself healthy and/or manage or prevent secondary complications)?
2b. What are some of the factors that have impeded success in your own self-management (definition of self-management: self-care activities which promote wellness or activities or strategies that you do to keep yourself healthy and/or manage or prevent secondary complications)?

E. CDSMP

- Describe the CDSMP and its modules and the fact that it is based on social cognitive learning theory (self-efficacy, outcome expectancy) – what are the advantages and disadvantages of this approach in a spinal cord injury population? Probe: How could it be changed to reflect family member/caregiver needs? What is helpful not as helpful about this program to individuals with spinal cord injury AND THEIR FAMILY MEMBER/CAREGIVERS?

Description of Self-Management Program:

The Stanford Chronic Disease Self-Management Program (CDSMP) is one of the most widely used self-management programs (Lorig et al., 1999; 2001). The Stanford CDSMP seeks to provide patients with the confidence and skills to better manage their chronic medical conditions, regardless of specific diagnosis (Lorig et al., 1999a; 2001). Individuals (non-health care professionals) who deliver the program are given a great deal of training so that the program is delivered in a consistent manner. For example, people with personal experience with one or more chronic conditions must successfully complete an intensive and standardized 4.5-day long training program to become facilitators or lay leaders certified to provide the CDSMP. Pairs of certified facilitators deliver the intervention with the use of a Leaders’ manual (i.e., to ensure consistency of content) to groups of 8-10 participants over 6 weekly sessions. Each session lasts approximately 2 hours, and is delivered in community settings (e.g., church halls).
The CDSMP covers generic topics including: an overview of self-management principles, exercise, pain and fatigue management, relaxation techniques (e.g., guided imagery and breathing exercises), dealing with depression, nutrition, communicating with family and health professionals, problem solving, and goal setting. Goals should be achieved during the following week, be personally relevant, achievable, challenging, have definite outcomes, and depend largely upon a person’s own efforts. Participants report back to the group on their achievements at the next weekly session. The format of the course is largely participatory and interactive, with short ‘lecturettes’ to introduce topics, group discussion, problem solving, role plays, and mastery experience (i.e., trying out the skills introduced on the course). Participants are encouraged to apply these generic skills to their own situation. Specifically, participants are taught to use behaviour change “action plans”, to use an organized approach to solving common self-management problems, and are given lots of opportunities to practice these skills and receive feedback on their performance (Jerant et al., 2005).

F. Wrap-up Questions

- Is there anything else I haven’t asked you about that you’d like to add?
- The responses you have provided may stimulate some additional questions or need for further clarification. If so, may we contact you in the future?

*Explain rest of process (e.g., that the results of the studies will be shared with participants…)*
Appendix F

Chapters 3 and 4: Semi-structured Interview Guide for Managers (Phase I)

Interview Guide for Rehabilitation and Acute Care Managers in Ontario

A. Background Information

Date of Interview:

Time of Interview:

Thank individual for participating, go over consent form and have them verbally agree to participate, explain process, how confidentiality and anonymity will be protected, etc. Underscore the fact that we are having a conversation; it is his or her experiences and input that are important. Underscore that they don’t have to answer any questions that they are uncomfortable answering.

B. Warm-up and Establishing Rapport

- It would be nice if you could let me know a little about yourself [this information may have been obtained ahead of time]:
  - Position
  - Number of years in position
  - Age
  - Sex
  - Rehabilitation or acute Care?
  - Number of patients on unit/in program/number of beds
### C. Questions for Rehabilitation and Acute Care Managers in Ontario

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<tr>
<th>Completed</th>
<th>Questions</th>
<th>Notes</th>
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<tr>
<td><strong>Meaning of self-management</strong>&lt;br&gt;1. What is self-management from your perspective?&lt;br&gt;OR&lt;br&gt;What comes to mind when you hear the phrase self-management?&lt;br&gt;<strong>Probes:</strong> Examples of self-management include changing dressings (medically-based), communicating with physicians (skill-based), seek social support? What is the ultimate goal of self-management?</td>
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<td><strong>Patients</strong>&lt;br&gt;2. What sort of self-management strategies are currently provided for patients in your program?&lt;br&gt;3. What could be added to your program to assist patients with self-management support/skills?&lt;br&gt;<strong>Probes:</strong> Any barriers, any facilitators to making this addition at the individual, provider, and/or policy levels?&lt;br&gt;4. What do you believe are the facilitators to self-management for patients in the community?&lt;br&gt;<strong>Probes:</strong> Again at the individual, provider, and/or policy levels?&lt;br&gt;5. What do you believe are the barriers to self-management for patients in the community?&lt;br&gt;<strong>Probes:</strong> Again at the individual, provider, and/or policy levels?</td>
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<td><strong>Family members/caregivers</strong>&lt;br&gt;6. What sort of self-management strategies are currently provided for family members or caregivers in your program?&lt;br&gt;7. What could be added to your program to assist family members or caregivers with self-management support/skills?&lt;br&gt;<strong>Probes:</strong> Any barriers, any facilitators to making this addition at the individual, provider, and/or policy levels?</td>
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<td>Completed</td>
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|           | 8. In your opinion, what facilitates self-management for family members or caregivers in the community?  
**Probes:** Again at the individual, provider, and/or policy levels?  
9. What do you believe are the barriers to self-management for family members or caregivers in the community?  
**Probes:** Again at the individual, provider, and/or policy levels? |       |
|           | **Reflections on the CDSMP**  
10. Describe the CDSMP (as below). Are you aware of this program/what are your thoughts on this program?  
**Probes:** Would this program be appropriate or helpful/not helpful in your program? Is it more appropriate or helpful/not helpful in the community setting? Why or why not? Would this program be useful or helpful/not helpful for family members/caregivers? |       |

* Community is defined as outside the health care setting (e.g., the rehabilitation setting).
Description of Self-Management Program:  

The Stanford Chronic Disease Self-Management Program (CDSMP) is one of the most widely used self-management programs (Lorig et al., 1999; 2001). The Stanford CDSMP seeks to provide patients with the confidence and skills to better manage their chronic medical conditions, regardless of specific diagnosis (Lorig et al., 1999a; 2001). Individuals (non-health care professionals) who deliver the program are given a great deal of training so that the program is delivered in a consistent manner. For example, people with personal experience with one or more chronic conditions must successfully complete an intensive and standardized 4.5-day long training program to become facilitators or lay leaders certified to provide the CDSMP. Pairs of certified facilitators deliver the intervention with the use of a Leaders’ manual (i.e., to ensure consistency of content) to groups of 8-10 participants over 6 weekly sessions. Each session lasts approximately 2 hours, and is delivered in community settings (e.g., church halls).

The CDSMP covers generic topics including: an overview of self-management principles, exercise, pain and fatigue management, relaxation techniques (e.g., guided imagery and breathing exercises), dealing with depression, nutrition, communicating with family and health professionals, problem solving, and goal setting. Goals should be achieved during the following week, be personally relevant, achievable, challenging, have definite outcomes, and depend largely upon a person’s own efforts. Participants report back to the group on their achievements at the next weekly session. The format of the course is largely participatory and interactive, with short ‘lecturettes’ to introduce topics, group discussion, problem solving, role plays, and mastery experience (i.e., trying out the skills introduced on the course). Participants are encouraged to apply these generic skills to their own situation. Specifically, participants are taught to use behaviour change “action plans”, to use an organized approach to solving common self-management problems, and are given lots of opportunities to practice these skills and receive feedback on their performance (Jerant et al., 2005).

D. Wrap-up Questions

- Is there anything else I haven’t asked you about that you’d still like to add regarding self-management programs?
- The responses you have provided may stimulate some additional questions or need for further clarification. If so, may we contact you in the future? Explain rest of process (e.g., that the results of the studies will be shared with participants…)}
Appendix G

Chapters 5 and 6: Research Ethics Board Amendment Approval Letter (Phase II)

PROTOCOL REFERENCE # 26429

November 1, 2012

Dr. Susan Jaglal
DEPT OF PHYSICAL THERAPY
FACULTY OF MEDICINE

Ms. Sarah Munce
DEPT OF PHYSICAL THERAPY
FACULTY OF MEDICINE

Dear Dr. Jaglal and Ms. Sarah Munce,

Re: Your research protocol entitled, "Considerations for self-management support to reduce secondary implications for individudals with traumatic spinal cord injury (SCI)"

We are writing to advise you that a member of the Health Sciences Research Ethics Board (REB) has granted approval to an amendment (Received October 17, 2012) to the above-referenced research protocol under the REB's delegated review process.

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

Best wishes for the successful completion of your research.

Yours sincerely,

Judith Friedland, Ph.D.
REB Chair

Daniel Gyewu
REB Manager
PART I – Background and Descriptive Information

1. What is your age?


2. What is your sex?

- Male
- Female
- Other, please specify: ______________________

3. What is your marital status?

- Married
- Living common-law
- Widowed
- Separated
- Divorced
- Single, never married

4. What racial or cultural group do you belong to?

- White
- South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
- Chinese
- Black
5. What is the highest degree, certificate or diploma you have completed?

- Less than high school diploma or its equivalent
- High school diploma or a high school equivalency certificate
- Trade certificate or diploma
- College, CEGEP or other non-university certificate or diploma (other than trades certificates or diplomas)
- University certificate or diploma below the bachelor’s level
- Bachelor’s degree (e.g., B.A., B.Sc., LL.B.)
- University certificate, diploma or degree above the bachelor’s level

6. What province do you currently live in?

- Newfoundland and Labrador
- Prince Edward Island
- New Brunswick
- Quebec
- Ontario
- Manitoba
- Saskatchewan
- Alberta
- British Columbia
7. What is the size of your community?

- One million or more people
- 250,000 to 999,999 people
- 50,000 to 249,999 people
- 20,000 to 49,999 people
- 2,500 to 19,999 people
- 2,499 people or less
- Don’t know

8a. Do you have children?

- Yes
- No

8b. If YES: How many children do you have?

9. Who are you currently living with? (check all that apply)

- Partner/spouse
- Family member(s)
- Paid attendant
- Alone
- Other, please specify... ________________
10. Who would you identify as your primary caregiver? (check one response only)
- Spouse
- Sibling
- Parent(s)
- Son or Daughter
- Nurse
- Attendant
- I don't have a primary caregiver
- Other, please specify... ______________________

11. What type of setting do you currently live in? (check one response only)
- Home without health services
- Home with health services
- Apartment without health services
- Apartment with health services
- Assisted living facility
- Other, please specify... ______________________

12. What is the level of your injury?
- Cervical
- Thoracic
- Lumbar
- Don’t know

13. Is your injury complete or incomplete?
- Complete
- Incomplete
14. Are you a person with
- Quadriplegia
- Paraplegia
- Don’t know

15. When did your injury occur (i.e., month, year)?

16. How did your injury occur?
- Sport
- Assault (blunt)
- Assault (penetrating)
- Fall
- Transport or Motor Vehicle Collision
- Other, please specify... ______________________
- Unspecified or unknown

17. Did you have a traumatic brain injury as a result of your injury in addition to your spinal cord injury?
- Yes
- No
- Don’t know

Contact with Health Professionals/Health Care Utilization

Now I’d like to ask you about your contacts with health professionals during the past 12 months, that is, from [date one year ago] to yesterday.
18a. Do you have a family physician?

- Yes
- No
- Don’t know

18b. If NO: Why do you not have a family physician? (check all that apply and then SKIP TO 18d)

- No family physicians available in the area
- Family physicians in the area are not taking new patients
- Have not tried to contact one
- Had a family physicians who left or retired
- Other, please specify... ______________________

18c. In the past 12 months, have you seen your family physician due to any of the following health problems? (check all that apply)

- Problems with sudden bouts of high blood pressure, intense sweating (i.e., autonomic dysreflexia)
- Pressure ulcers (i.e., decubitus ulcers)
- Bladder dysfunction (e.g., urinary tract infection(s))
- Pneumonia
- Low blood pressure
- Bowel issues
- Blood clots in the leg (i.e., deep venous thrombosis (DVT))
- Blood clots in the lung (i.e., deep venous thrombosis (DVT))
- Depression
- Pain
- Injury (e.g., fracture)
- Other, please specify... ______________________
- Don’t know
18d. In the past 12 months, what specialist physicians have you seen? (check all that apply)

☐ Physiatrist
☐ Neurologist
☐ Urologist
☐ Neurosurgeon
☐ Other, please specify... ______________________
☐ None; If NO: SKIP TO 18f
☐ Don’t know

18e. In the past 12 months, have you seen your specialist physician(s) due to any of the following health problems (check all that apply)?

☐ Problems with sudden bouts of high blood pressure, intense sweating (i.e., autonomic dysreflexia)
☐ Pressure ulcers (i.e., decubitus ulcers)
☐ Bladder dysfunction (e.g., urinary tract infection(s))
☐ Pneumonia
☐ Low blood pressure
☐ Bowel issues
☐ Blood clots in the leg (i.e., deep venous thrombosis (DVT))
☐ Blood clots in the lung (i.e., deep venous thrombosis (DVT))
☐ Depression
☐ Pain
☐ Injury (e.g., fracture)
☐ Other, please specify... ______________________
☐ Don’t know

18f. In the past 12 months, have you visited the emergency department?

☐ Yes
No; If NO: SKIP TO 18h

Don’t know

18g. In the past 12 months, have you visited the emergency department due to any of the following health problems? (check all that apply)

☐ Problems with sudden bouts of high blood pressure, intense sweating (i.e., autonomic dysreflexia)
☐ Pressure ulcers (i.e., decubitus ulcers)
☐ Bladder dysfunction (e.g., urinary tract infection(s))
☐ Pneumonia
☐ Low blood pressure
☐ Bowel issues
☐ Blood clots in the leg (i.e., deep venous thrombosis (DVT))
☐ Blood clots in the lung (i.e., deep venous thrombosis (DVT))
☐ Depression
☐ Pain
☐ Injury (e.g., fracture)
☐ Other, please specify... ______________________

Don’t know

18h. In the past 12 months, have you been admitted to hospital (i.e., been a patient overnight in a hospital)?

☐ Yes
☐ No If NO: SKIP TO 19a
☐ Don’t know

18i. In the past 12 months, have you been admitted to hospital due to any of the following health problems? (check all that apply)

☐ Problems with sudden bouts of high blood pressure, intense sweating (i.e., autonomic dysreflexia)
Pressure ulcers (i.e., decubitus ulcers)
Bladder dysfunction (e.g., urinary tract infection(s))
Pneumonia
Low blood pressure
Bowel issues
Blood clots in the leg (i.e., deep venous thrombosis (DVT))
Blood clots in the lung (i.e., deep venous thrombosis (DVT))
Depression
Pain
Injury (e.g., fracture)
Other, please specify... ______________________
Don't know

Health Care System Satisfaction

Now, a few questions about health care services you have received in your province.

19a. Overall, how would you rate the availability of health care services in your province? Would you say it is:

- Excellent
- Good
- Fair
- Poor
- Don't know

19b. Overall, how would you rate the availability of health care services in your community?

- Excellent
- Good
- Fair
19c. Overall, how would you rate the quality of the health care services that are available in your community?

- Excellent
- Good
- Fair
- Poor
- Don’t know

PART II – Components of a Targeted Self-Management Support Program

1. How would you rate the following items in terms of their importance in a self-management support program to reduce health problems associated with spinal cord injury and promote wellness?

<table>
<thead>
<tr>
<th>Item</th>
<th>Very Unimportant</th>
<th>Unimportant</th>
<th>Neither Important or Unimportant</th>
<th>Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Pain management</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Fatigue management</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Relaxation techniques (e.g., guided imagery and breathing exercises)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Dealing with depression</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Nutrition</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Communicating with family</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Communicating with</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
health care professionals
Problem solving  ○  ○  ○  ○  ○  ○  ○  ○
Goal setting/action planning  ○  ○  ○  ○  ○  ○  ○  ○

2. How would you rate the following other items in terms of their importance in a self-management support program to reduce health problems associated with spinal cord injury and promote wellness?

<table>
<thead>
<tr>
<th>Item</th>
<th>Very Important</th>
<th>Unimportant</th>
<th>Neither Important or Unimportant</th>
<th>Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information/education on aging with a spinal cord injury</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Information/education on sexuality and spinal cord injury</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Relationship issues (e.g., with your spouse)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Confidence</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Decision-making abilities</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Can provide mentorship opportunities</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Can receive mentorship opportunities</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Learning about volunteer opportunities</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Skills to enter/re-enter to job market</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Issues of transitioning from rehabilitation to the community</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
3. Are there other components that could be added to a self-management support program to reduce health problems associated with spinal cord injury and promote wellness?

4. How would you rate the following items in terms of their importance in a self-management support program for your family member/caregiver?

<table>
<thead>
<tr>
<th>Item</th>
<th>Very Important</th>
<th>Unimportant</th>
<th>Neither Important or Unimportant</th>
<th>Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information/education on aging with a spinal cord injury</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Information/education on sexuality and spinal cord injury</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Relationship issues</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Specific emotional support for caregivers/family members themselves</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Practical support for caregivers/family members themselves (e.g., learning skills to assist you with bladder/bowel management)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>

5. Are there other components that could be added to a self-management support program to reduce health problems associated with spinal cord injury and promote wellness for your family member/caregiver?
6. What do you think would be the best delivery format for a self-management support program? (check one response only)

- Internet-based (e.g., webinar, blog entries)
- Telehealth system
- (A series of) DVDs
- Brochure
- In person, in the community (e.g., such as a church hall)
- By telephone
- Other, please specify... ______________________

7. Thinking about the best delivery format for a self-management support program that you selected above, with whom do you think the program would be best delivered? (check one response only)

- One-on-one (i.e., one facilitator to one client)
- Individually (e.g., the client views a webinar individually)
- In a group setting with other individuals with traumatic SCI
- In a group setting with other individuals with traumatic SCI together with their caregivers/family members
- In a group setting with other individuals with traumatic SCI together with their caregivers/family members, but with opportunities for individuals with SCI and their caregivers/family members to have separate discussions
- Other, please specify... ______________________

8. In order to best suit your needs, what do you think are some other considerations for the make-up of the self-management support program? (check all that apply)

- The program should have individuals of a similar age
- The program should have individuals of the same gender
- The program should have individuals with a similar level of injury
- The program could have individuals with non-traumatic spinal cord
The program could have individuals in a wheelchair (i.e., they may have another neurological condition, but they don’t necessarily have a spinal cord injury)
Other, please specify... ________________

9. In your opinion, what do you think would be the optimal number of sessions for a self-management support program?

10. In your opinion, how long do you think each session should last (in hours)?

11. In your opinion, when would be the best time to introduce or start a self-management support program for individuals with a traumatic spinal cord injury? Thinking about this another way, and based on your own experience, when would you have been ready to have first received a self-management support program? (check one response only)

○ During the acute care period (i.e., shortly after the injury, in hospital)
○ During the rehabilitation period
○ During the transition from rehabilitation to the community
○ Once accustomed to living in the community (e.g., ≥ 18 months after the injury)
○ Other, please specify... ________________

12. Again, thinking about your own experiences and your recovery trajectory, at what point(s) would a self-management support program have been useful/helpful (check all that apply)?

○ During the acute care period (i.e., shortly after the injury, in hospital)
○ During the rehabilitation period
○ During the transition from rehabilitation to the community
Once accustomed to living in the community (e.g., ≥ 18 months after the injury)
Other, please specify... ______________________

13a. At the end of a self-management support program, do you think it would be helpful to have a follow-up self-management session(s) or program?

- Yes
- No
- Don’t know

13b. If YES: What form would this follow up take?

- Meet again as a group 1 or 2 years after the completion of the first program
- Regular contact with an individual(s) from the group (e.g., another individual with a spinal cord injury)
- Regular contact with a health care professional, such as a nurse
- Other, please specify... ______________________

14. Who do you think should deliver a self-management support program? (check one response only)

- Health care professional(s) such as a nurse, rehabilitation specialist
- Non-health care professionals
- Individual(s) who has/have a traumatic spinal cord injury
- Individual(s) who has/have a neurological condition (e.g., multiple sclerosis)
- Caregiver of an individual with a traumatic spinal cord injury
- Combination of any of above choices (Specify): ______________________
- Other, please specify... ______________________
15. Who do you think should be responsible for organizing the self-management program (e.g., informing patients about the existence of the program, training staff to deliver the program, advertising the program)? (check one response only)

- Family physician
- Physiatrist
- Neurologist
- Case manager
- Staff in the acute care team
- Staff in the rehabilitation team
- An organization such as the Canadian Paraplegic Association
- Staff in the home care team
- Other, please specify... ______________________

16. How important is it for a self-management program to be developed for individuals with traumatic spinal cord injury?

- Very Unimportant
- Unimportant
- Neither Important or Unimportant
- Important
- Very Important

PART III – Consumer Characteristics

1. Moorong Self-Efficacy Scale (MSES) (Middleton et al., 2003)

1. I can maintain my personal hygiene with or without help.
2. I can avoid having bowel accidents.

1=Very Uncertain 2 3 4 5 6 7=Very Certain

○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○
3. I can participate as an active member of the household. ☐ ☐ ☐ ☐ ☐ ☐ ☐

4. I can maintain relationships in my family. ☐ ☐ ☐ ☐ ☐ ☐ ☐

5. I can get out of my house whenever I need to. ☐ ☐ ☐ ☐ ☐ ☐ ☐

6. I can have a satisfying sexual relationship. ☐ ☐ ☐ ☐ ☐ ☐ ☐

7. I can enjoy spending time with my friends. ☐ ☐ ☐ ☐ ☐ ☐ ☐

8. I can find hobbies and leisure pursuits that interest me. ☐ ☐ ☐ ☐ ☐ ☐ ☐

9. I can maintain contact with people who are important to me. ☐ ☐ ☐ ☐ ☐ ☐ ☐

10. I can deal with unexpected problems that come up in life. ☐ ☐ ☐ ☐ ☐ ☐ ☐

11. I can imagine being able to work at some time in the future. ☐ ☐ ☐ ☐ ☐ ☐ ☐

12. I can accomplish most things I set out to do. ☐ ☐ ☐ ☐ ☐ ☐ ☐

13. When trying to learn something new, I will persist until I am successful. ☐ ☐ ☐ ☐ ☐ ☐ ☐

14. When I see someone I would like to meet, I am able to make the first contact. ☐ ☐ ☐ ☐ ☐ ☐ ☐

15. I can maintain good health and well-being. ☐ ☐ ☐ ☐ ☐ ☐ ☐

16. I can imagine having a fulfilling lifestyle in the future. ☐ ☐ ☐ ☐ ☐ ☐ ☐

---

2. Which of the following elements of self-management are you already incorporating in your daily life to reduce health problems and/or increase well-being? (check all that apply)

- Engaging in exercise
- Practicing pain and fatigue management
- Practicing relaxation techniques (e.g., guided imagery and breathing exercises)
- Dealing with depression
- Learning about nutrition
- Communicating with family
3. Mastery or Locus of Control (Pearlin and Schooler Mastery Scale, 1978)

Now a series of statements that people might use to describe themselves. Please tell me if you strongly agree, agree, neither agree nor disagree, disagree, or strongly disagree.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. You have little control over the things that happen to you.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>2. There is really no way you can solve some of the problems you have.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>3. There is little you can do to change many of the important things in your life.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>4. You often feel helpless in dealing with problems of life.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>5. Sometimes you feel that you are being pushed around in life.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>6. What happens to you in the future mostly depends on you.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>7. You can do just about anything you really set your mind to.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

4. Patient Activation Measure (Hibbard et al., 2005)

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think others want you to say. If the statement does not apply to you, click N/A.

<table>
<thead>
<tr>
<th>Disagree Strongly</th>
<th>Disagree</th>
<th>Agree</th>
<th>Agree Strongly</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When all is said and done, I am the person who is responsible for taking care of my health</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
2. Taking an active role in my own health care is the most important thing that affects my health

3. I am confident I can help prevent or reduce problems associated with my health

4. I know what each of my prescribed medications do

5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself

6. I am confident that I can tell a doctor concerns I have even when he or she does not ask

7. I am confident that I can follow through on medical treatments I may need to do at home

8. I understand my health problems and what causes them

9. I know what treatments are available for my health problems

10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising

11. I know how to prevent problems with my health

12. I am confident I can figure out solutions when new problems arise with my health

13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress

Insignia Health. "Patient Activation Measure; Copyright © 2003-2010, University of Oregon. All Rights reserved"

5. Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)

Read each item below and click or mark the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.
<table>
<thead>
<tr>
<th></th>
<th>Most of the time</th>
<th>A lot of the time</th>
<th>From time to time, occasionally</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel tense or ‘wound up’</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>I still enjoy the things I used to enjoy</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>I get a sort of frightened feeling as if something awful is about to happen</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>I can laugh and see the funny side of things</td>
<td>As much as I always could</td>
<td>Not quite so much now</td>
<td>Definitely not so much now</td>
<td>Not at all</td>
</tr>
<tr>
<td>Worrying thoughts go through my mind</td>
<td>A great deal of the time</td>
<td>A lot of the time</td>
<td>Not too often</td>
<td>Very little</td>
</tr>
<tr>
<td>I feel cheerful</td>
<td>Never</td>
<td>Not often</td>
<td>Sometimes</td>
<td>Most of the time</td>
</tr>
<tr>
<td>I can sit at ease and feel relaxed</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>I feel as if I am slowed down</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>I get a sort of frightened feeling like ‘butterflies’ in the stomach</td>
<td>Not at all</td>
<td>Occasionally</td>
<td>Quite often</td>
<td>Very often</td>
</tr>
<tr>
<td></td>
<td>Definitely</td>
<td>I don't take as much care as I should</td>
<td>I may not take quite as much care</td>
<td>I take just as much care as ever</td>
</tr>
<tr>
<td>-----------------------------------------------------------------</td>
<td>-------------------</td>
<td>--------------------------------------</td>
<td>-----------------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>I have lost interest in my appearance</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>I feel restless as if I have to be on the move</td>
<td>Very much indeed</td>
<td>Quite a lot</td>
<td>Not very much</td>
<td>Not at all</td>
</tr>
<tr>
<td>I look forward with enjoyment to things</td>
<td>As much as I ever did</td>
<td>Rather less than I used to</td>
<td>Definitely less than I used to</td>
<td>Hardly at all</td>
</tr>
<tr>
<td>I get sudden feelings of panic</td>
<td>Very often indeed</td>
<td>Quite often</td>
<td>Not very often</td>
<td>Not at all</td>
</tr>
<tr>
<td>I can enjoy a good book or radio or television programme</td>
<td>Often</td>
<td>Sometimes</td>
<td>Not often</td>
<td>Very seldom</td>
</tr>
</tbody>
</table>

When you are feeling down in the dumps, feeling pain or having other unpleasant symptoms, how often do you (please identify one for each question):

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Fairly Often</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Try to feel distant from the discomfort and pretend that it is not part of your body.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. Don’t think of it as discomfort but as some other sensation, like a warm, numb feeling.</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>3. Play mental games or sing songs to keep your mind off the discomfort.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>4. Practice progressive muscle relaxation.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Talk to yourself in positive ways.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


When you visit your doctor, how often do you do the following (please identify one for each question):

<table>
<thead>
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<th>Question</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Fairly Often</th>
<th>Very Often</th>
<th>Always</th>
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<td></td>
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</tbody>
</table>
1. Prepare a list of questions for your doctor
2. Ask questions about the things you want to know and things you don't understand about your treatment.
3. Discuss any personal problems that may be related to your illness.

THANK YOU VERY MUCH!!! Your participation in spinal cord injury research is important. People who work in the field of spinal cord injury use the information to provide better care now and in the future. If you have any questions or concerns regarding the survey, you can contact Sarah Munce at sarah.munce@utoronto.ca or at toll-free at 1-855-946-7902.

Please send us your address so that we can mail you your $10.00 gift certificate.