An Exploration of Support Needs of Family Caregivers of Individuals with Spinal Cord Injury: A Qualitative Study

by

Gayathiri Jeyathevan

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Institute of Health Policy, Management and Evaluation
University of Toronto

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Abstract

There is a gap in evidence with respect to the specific support needs of family caregivers of individuals with spinal cord injury (SCI). The objectives of this thesis include determining: 1) the perceived facilitators and barriers to undertaking and sustaining the caregiving role; 2) the types of support needed by individuals with SCI, and the factors related to the need for more support; 3) the skills needed by SCI family caregivers to enhance competency in caregiving; and 4) how caregivers and care recipients negotiate changes within the relationship post-SCI. This research used a qualitative descriptive approach with an exploratory design. Thirty-four interviews (19 individuals with SCI, 15 family caregivers) were conducted. In the first paper, the following four facilitators to caregiving were identified: access to community support services, positive coping in relationship, social support, and mastery of caregiving roles. Conversely, the following six barriers to caregiving were identified: lack of access to community resources, lack of knowledge about resources and formal training, fragmented continuity of care, negative coping in relationship, role strain, and caregiver injury or illness. In the second paper, the following types of support needed by individuals with SCI were identified: practical, emotional and advocacy. The following factors associated with the need for more support were also identified: a higher level of injury, greater frequency of secondary health conditions and age of
the care recipient. In the third paper, twenty-nine SCI family caregiving skills were identified and grouped into six caregiving processes signifying the multiple dimensions of the SCI caregiving role. In the final paper, the following four factors that challenged relationship stability were identified: protective behaviours, asymmetrical dependency, loss of sex and intimacy, and difficulty adapting. Also, the following four strategies used by care recipients and caregivers to maintain/re-build their relationships were identified: interdependence, shifting commonalities, adding creativity into routine, and creating a new normal. These findings could serve to facilitate prospective planning of sustainable support for family caregivers as well as improve the health outcomes of individuals with SCI.
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List of Abbreviations

Activities of Daily Living (ADLs)
Caregiver (CG)
Care recipient (CR)
Hamilton Health Sciences (HHS)
Intermittent catheterization (IC)
Knowledge-to-Action (KTA)
Local Health Integration Network (LHIN)
Non-traumatic spinal cord injury (NTSCI)
Personal support worker (PSW)
Problem-solving training (PST)
Randomized controlled trial (RCT)
Rick Hansen Institute (RHI)
Spinal cord injury (SCI)
Spinal Cord Injury Ontario (SCIO)
Theoretical Domains Framework (TDF)
Toronto Rehabilitation Institution (TRI)
Traumatic spinal cord injury (TSCI)
Urinary tract infection (UTI)
Chapter 1
Introduction

The onset of spinal cord injury (SCI) is devastating, and has a profound impact on the physiological, functional, social, economic and psychological well-being of the individual. Although rehabilitation allows the individuals to learn how to navigate through life with a SCI, the trend of decreasing length-of-stay in rehabilitation centres has resulted in individuals with SCI entering the community after a limited time for adjustment to the physical and psychological changes post-injury. The implication being having less knowledge and expertise in self-care skills to be as independent as possible (McColl et al., 2012) and reliance on family members for assistance with a range of services, which were formerly provided by regulated health care professionals (Schulz et al., 2009) during inpatient care.

Studies have demonstrated that caregivers of individuals with SCI can experience challenges and difficulties associated with providing care in the long-term (Nogueira et al., 2012; Post, Bloemen & de Witte, 2005). Indeed, comparable to individuals with SCI, their family caregivers also face adjustment challenges; whereby, they are often required to reconstruct their lives, and start an “unexpected career” in order to provide support with activities of daily living (ADLs), personal care, and emotional support to their family member with a disability (Archbold et al., 1990; Dickson et al., 2010). Furthermore, the early discharge of individuals with SCI often leaves family caregivers with limited time for learning caregiving skills; thus, feeling unprepared to assume the caregiver role (Robinson-Whelen & Rintala, 2003). Although family caregivers make an important contribution to the care processes and overall quality of life of individuals
with SCI, ironically, many caregivers do not receive sufficient support and experience negative effects of caregiving, which threatens the sustainability of the care provided.

In order to continue providing care, family caregivers require support so that their own physical, emotional and mental health needs are addressed. However, surprisingly little is known about the specific support needs of family caregivers of individuals with SCI. Particularly, there is a paucity of literature exploring the facilitators and barriers experienced in providing care, factors related to the need for more support, and skills needed to enhance competency in caregiving to individuals with SCI in the community. This thesis aims to address these gaps by gathering evidence on the diverse support needs of family caregivers of individuals with SCI. By improving our understanding of their needs, we will be better placed to provide relevant support based on current best practices, which could promote sustained family involvement in the caregiving process and improve the health and wellbeing of both the individuals with SCI and their family caregivers.

This thesis is comprised of eight chapters. In chapter two, I set the stage for the thesis by reviewing the literature on the epidemiology of SCI, roles and responsibilities of family caregivers, burden of care and contributing factors to burden of care, sustained family involvement in caregiving, existing interventions to support caregivers, and the unmet supportive care needs of family caregivers of individuals with SCI, as well as the study rationale and research objectives. Chapter three provides an overview of the research methods for the study. Chapters four to seven include four distinct but connected papers reporting on the qualitative study conducted for this thesis. Chapter four describes the perceived facilitators and barriers to supporting individuals with SCI in the community. Chapter five highlights the factors associated with the need for more support for individuals with SCI living in the community. Chapter six
explains the breadth of caregiving skills needed to enhance SCI related caregiving competency. Finally, chapter seven, an emerging theme, describes the factors that may challenge the stability of relationships, as well the strategies used by caregivers and care recipients to negotiate changes within their relationships. Chapters four to seven are written in a format for publication as individual articles in peer-reviewed journals. As a result, there may be overlap of information across the chapters. The concluding chapter (Chapter 8) highlights: the synthesis of the key findings, which discusses SCI caregiver support needs in the context of the literature, as well as in the context of current policies and practices; the key recommendations to meet support needs of caregivers based on the findings; the strengths and limitations of the study; suggestions for future research in SCI caregiving and supportive care; and knowledge translation and policy implications of this research.
Chapter 2
Background, Rationale and Research Objectives

2.1 Description and Epidemiology of Spinal Cord Injury

A SCI results from dysfunction or damage to the spinal cord, which results in impairments to the sensory, motor and autonomic functions (American Spinal Injury Association, 2008). Paralysis from a SCI can be categorized as either: paraplegia which is a damage to the thoracic, lumbar or sacral spinal cord; or tetraplegia which occurs with damage to the cervical cord (Noonan et al., 2012). Causes for SCI are categorized as either traumatic or non-traumatic. Traumatic spinal cord injuries (TSCI) are caused by a sudden traumatic blow to the spine. The most common causes of TSCI include: falls, motor vehicle collisions, or violence (Noonan et al., 2012). The pathogenesis of non-traumatic spinal cord injury (NTSCI) includes etiologies such as vertebral spondylosis, tumorous compression, vascular ischemia, and congenital disease (Adams & Salam-Adams, 1991; Dawson & Potts, 1991; Schmidt & Markovchick, 1992; New, Rawicki & Bailey, 2002). TSCI often occurs in a younger (age 15-29) male population (Noonan et al., 2012; Maharaj, 1996; Couris et al., 2010), while individuals with NTSCI are older (age 55-85) and more likely to be female (Noonan et al., 2012; New, Simmonds & Stevermuer, 2011). The age-adjusted discharge incidence of TSCI in Canada is approximately 41 per million, while the estimated discharge incidence for NTSCI is 68 per million. The national prevalence of SCI is estimated to be 85,556 persons (51% of TSCI and 49% of NTSCI) (Noonan et al., 2012). It is anticipated that there will be a dramatic increase in the incidence of NTSCI in Canada over the coming two decades as a result of the aging population (Farry & Baxter, 2010). This increased number of individuals with SCI can have a marked impact not only at the health system level (e.g., increased healthcare costs), but also on
the individuals themselves (e.g., physical, psychosocial, economic well-being of individuals with SCI and their family members/caregivers).

The impact of a SCI on the individual is considerable and often results in difficulties that are physical (Vissers et al., 2008), emotional (Znoj & Lude, 2002), psychosocial (Migliorini, Tonge & Taleporo, 2008), and economic (Munce et al., 2013). Several secondary health conditions arise from SCI, including pressure injuries, urinary tract infections, bowel and bladder dysfunctions, chronic pain, and spasticity (Noreau et al., 2000; Elliott & Rivera, 2003). The emotional impact of a SCI can lead to depression (Kemp, Krause & Adkins, 1999), anxiety (Kennedy & Rogers, 2000), alcohol and substance abuse (Tate et al., 2004), and a negative perception of one’s own physical and cognitive function (Murray et al., 2007). Psychosocial effects include increased social isolation (Hammell, 1994), difficulty with relationship/family adjustment (DeSanto-Madeya, 2009; Kreuter et al., 1998), decreased life satisfaction (Budh & Osterake, 2007), and decreased quality of life (Lidal et al., 2008). Lastly, economic consequences consist of lower employment (Post & Noreau, 2005), as well high medical and hospitalization costs (Priebe et al., 2007; Munce et al., 2013). When these challenges combine, they can impede an individual’s ability to function independently (Vissers et al., 2008; Thompson, 1999); as a result, family members may have to play an active role in providing support to the individual with SCI.

2.2 Family Caregivers of Individuals with Spinal Cord Injury

2.2.1 Description and Definition of Family Caregivers

Individuals with SCI living in the community are often supported by unpaid informal caregivers, which primarily includes family members (Post, Bloemen & de Witte, 2005). On the other hand, some family caregivers do not have a legally defined relationship or family kinship
with the care recipient, but are rather partners, friends or neighbours. Although the repercussions of SCI affect the entire family, usually one individual in the family assumes the primary caregiver role (Nogueira et al., 2012). The meaning of family caregiver can be explained by the caregiver identity theory (Montgomery & Kosloski, 2009). According to the theory, the role of caregiver emerges from an existing familial role, such as spouse, parent, or child. As the needs of the care recipient increases over time, the initial familial relationship transforms into a relationship distinguished by caregiving and corresponding changes in the caregiver’s role in relation to the care recipient (Montgomery & Kosloski, 2009). Furthermore, caregiver situations and context are considerably diverse. Family caregivers may or may not co-habit with the individual receiving care, and the care they provide may be episodic, daily, occasional, or of short or long duration (Schulz & Eden, 2016).

This thesis uses the terms “family caregivers” and “caregivers” interchangeably to refer to family members who assume the responsibility in providing physical and/or psychological assistance to the injured individual (details of what constitutes a family caregiver for this study are outlined in Chapter 3). The term “care recipient” is used to refer to the individuals with SCI.

2.2.2 Relationship between Family Caregivers and Care Recipients with Spinal Cord Injury

A family caregiver’s relationship to his/her injured family member may influence the undertaking of the primary caregiving role and level of support provided. Family caregivers of individuals with SCI are most often spouses and parents, as opposed to adult children, which is usually the case with the general elderly population requiring assistance (Ellenbogen et al., 2006). Also, the nature of the family relationships may impact the burden experienced and reported caregiver needs. Studies suggest that spouses of individuals with SCI suffer higher
levels of stress than other family members in assuming the caregiving role (Shewchuk, Richards & Elliott, 1998; Schulz et al., 1987). In their study exploring family needs and psychosocial functioning of caregivers of individuals with SCI, Arango-Lasprilla and colleagues (2010) reported that spouses often find the caregiving role was emotionally difficult, more so than other family members. A potential explanation being that the spouse of an individual with SCI may feel obligated to undertake the caregiving role in addition to their assumed spousal role, resulting in additional distress (Chan, 2000).

On the other hand, in a recent descriptive cross-sectional study evaluating the relationship between sociodemographic factors and level of burden among primary caregivers of individuals with SCI, the authors reported that parents experienced more burden as caregivers in comparison to the spousal caregivers. The authors of that study went on to explain that parents are often older than spousal caregivers, and therefore, experience greater physical burden (Khazaeipour et al., 2017) because they could be facing their own functional limitations (Thompson, 1999). Similar findings have been reported in studies of other neurological conditions. For example, a study by Serio and colleagues (1995) explored the needs of parent caregivers versus spousal caregivers after a brain injury. The authors highlighted that although a spouse whose partner sustains a brain injury may lose his/her confidant, economic support, sexual partner, household co-manager and child rearing assistant, they may have the option to divorce their injured partner. However, parents of adult offspring with brain injury may feel obligated to provide care for the rest of their lives (Serio et al., 1995). This indicates that the burden experienced by parent caregivers might be continuous compared to spousal caregivers.

2.2.3 Roles and Responsibilities of SCI Family Caregivers
Family caregivers, who often become the primary source of help for individuals with SCI, provide assistance with a range of activities, such as basic ADLs (e.g., bathing, dressing, and bowel and bladder management) (Shewchuk, Richards, & Elliott, 1998), instrumental ADLs (e.g., preparing meals, housekeeping, transportation, and managing finances) (Post, Bloemen & de Witte, 2005), and emotional support (Dickson et al., 2010). In undertaking these diverse caregiving responsibilities, caregivers must engage in ongoing cognitive and interpersonal processes including: continuous problem-solving and decision-making, effective communication (with healthcare professionals and other family members), and continual vigilance over the care recipient’s overall wellbeing (Gitlin & Wolff, 2012). In fact, caregivers of people with SCI have often been defined as the “secondary care team”, underscoring their critical role in filling the gaps that exist within the formal health care system (Guilcher et al., 2013).

2.3 Burden of Care Among SCI Family Caregivers

Although undertaking the caregiver role may improve the health-related quality of life of the individual with SCI, this often comes at a cost to the caregiver who may experience role overload (i.e., inability to balance ongoing demands of caregiving as well as personal obligations [Charlifue et al., 2016]). This, in turn, may lead to increased burden of care for the family caregiver (Donelan et al., 2002). The burden of care can be described as a multidimensional response to the negative appraisal and perceived stress as a result of providing care to the care recipient (Kim et al., 2012), which can be distinguished as either objective or subjective burden (Khazaeipour et al., 2017). Objective burden can be described as the external consequences, such as decline in financial resources (Khazaeipour et al., 2017) and dissolution of family relationships (Vagharseyyedin & Molazem, 2013) that result from direct caregiving tasks. Subjective burden is associated with the psychological consequences, such as emotional pain or
depression (Khazaeipour et al., 2017) reported by the caregiver based on his/her perception or appraisal of the caregiving experience (Adeosun, 2013).

As a result of the role overload associated with the multiple complex caregiving tasks, caregivers of individuals with SCI often experience significant physical strain (Schulz et al., 2009). SCI caregivers frequently report bodily pain (Blanes et al., 2007; Coleman et al., 2013) and poor physical health (Blanes et al., 2007; Weitzenkamp et al., 1997). Specifically, the regular, frequent physical nature of caregiving for individuals with SCI with tasks such as support with dressing, bathing and toileting along with performing rehabilitation exercises on a daily basis is notably stressful and tiring (Lynch & Cahalan, 2017). Furthermore, caregivers of people with SCI experience more frequent insufficient sleep (e.g., disturbed sleeping patterns, more days without sleep), and higher odds of coronary heart disease, obesity and hypertension in comparison to caregivers of those with other neurological conditions (LaVela et al., 2015; Nogueira et al., 2012).

The current literature suggests that caregivers of individuals with SCI also experience high levels of emotional stress (Vagharseyyedin & Molazem, 2013) and are likely to suffer from several adverse mental health outcomes, such as anxiety, depression, and stress (Post, Bloemen & de Witte, 2005; Arango-Lasprilla et al., 2010; Dreer et al., 2007; Manigandan et al., 2000). Given the time-consuming and tiring caregiving duties, caregivers of individuals with SCI often feel fatigued and depressed in their caregiving role (Charlifue et al., 2016). Consequently, these depressive feelings lead to heightened negative appraisal of the caregiving situation (e.g., increased hopelessness) that results in feelings of burden in the caregiving role (Secinti, Yavuz & Selcuk, 2017). Furthermore, SCI family caregivers may be at greater risk of psychological distress, in comparison to caregivers of individuals living with other chronic illnesses and
injuries, due to the unique challenges of providing care for complications particularly tied to SCI (e.g., constant monitoring for tissue injury and pressure injury management, and appropriate nutrition administration for bowel and bladder) (Nogueira et al., 2012), and the longer the duration of their caregiving period (Schulz et al., 2009). A study by Weitzenkamp and colleagues (1997) identified that spouses who have been providing care for more than 23 years to the individuals with SCI had higher levels of stress, depression and resentment in comparison to spouses who were not caregivers. In fact, several studies have also reported higher self-reported levels of psychological distress in caregivers of individuals with SCI in comparison to the individuals with SCI themselves (Weitzenkamp et al., 1997; Robinson-Whelen & Rintala, 2003; Chan, 2000).

Caregiving is often marked by an increase in social isolation for the caregiver that results in reduced involvement in social and leisure activities (Gajraj-Singh, 2011), as well as relationship challenges (Kreuter, 2000). For example, caregivers of individuals with SCI often experience increased burden due to increasing time spent providing care. Thus, they feel fatigued or do not have sufficient time to carry out other preferred activities (Gajraj-Singh, 2011), which consequently leads to increased social isolation (Rodakowsi et al., 2012). In addition, caregiving usually alters the balance of power in marriage and the family dynamics, which then increases the risk of separation or divorce (Kreuter, 2000). In fact, there is a significantly higher incidence of separations and divorces during the first three years post-injury (DeVivo & Fine, 1985). Reasons for divorces include: challenges adapting to new physical functions, difficulties maintaining the relationship, and being unwilling to live with the injured individual (Kreuter et al., 1998).

Finally, the injury and any ensuing change in employment status for the injured person is
likely to cause significant financial strain/burden on the family (Vaghaseyyedin & Molazem, 2013; Ellenbogen et al., 2006). For example, SCI usually results in significant direct financial costs related to the need for specific medical supplies, transportation, and housing modifications (Ellenbogen et al., 2006). In fact, caregivers of individuals with SCI reported more financial burden in comparison to caregivers of individuals with other neurological conditions (18% vs. 6%) (LaVela et al., 2015). Furthermore, if the individual with SCI was the primary wage earner of the family, there is an immediate income loss post-injury and thus, it becomes necessary for the non-injured family member/caregiver (e.g., spouse, parent) to enter or return to the workforce (Ellenbogen et al., 2006). On the other hand, as a result of taking on the caregiving role, some caregivers either have to go into early retirement or work reduced hours (Fast et al., 2013; Ellenbogen et al., 2006), resulting in additional financial burden.

2.3.1 Factors Contributing to Burden of Care

The following highlights several mediating factors that influence the perceived burden experienced by SCI family caregivers.

Level of Injury

Generally, individuals with a high level of injury, such as tetraplegia, are more dependent on their caregivers for assistance on a daily basis and require more hours of care. Consequently, the family caregivers experience a higher level of burden (Khazaeipour et al., 2017; Nogueira et al., 2012). Indeed, caregiving requires extensive commitment to the additional responsibilities related to the role (Arango-Lasprilla et al., 2010). In a recent study by Charlifue and colleagues (2016), it was reported that family caregivers dedicate approximately 8 hours per day to providing assistance to people with SCI. Owing to the caregiving duties particularly tied to the
level of injury, the level of assistance provided in ADLs and time spent in care (i.e., number of hours of caregiving per day) are also strong predictors of burden among caregivers of individuals with SCI. In other words, burden increases simultaneously with increasing time spent providing support with ADLs to the care recipients on a daily basis (Gajraj-Singh, 2011).

**Older Age**

Older individuals with SCI often require a high level of assistance at home. Specifically, individuals with SCI who are aging, require assistance approximately twice as often in comparison to aging individuals in the general population, and need personal care assistance up to 7 times more often (Eisenberg & Saltz, 2010). Given that the majority of family caregivers of individuals with SCI are spouses and parents (Ellenbogen et al., 2006), over time these caregivers are also becoming older and could be facing their own functional limitations (Thompson, 1999). Older caregivers experience significantly greater burden than younger caregivers (Khazaeipour et al., 2017; Post, Bloemen & de Witte, 2005). These elderly caregivers may be more burdened due to their general ability, energy and having less adaptation capability for the caregiving role in comparison to the younger caregivers (Khazaeipour et al., 2017) who may display more physical resilience. In addition, older caregivers may also have developed their own health problems (e.g., chronic illnesses) and physical disabilities that limit their ability to provide care to their injured family member (Arango-Lasprilla et al., 2010).

**Gender**

In the literature overall, females report higher levels of burden caring for a family member with SCI compared to males. This is perhaps due to variance in actual levels of support provided (Post, Bloemen & de Witte, 2005). For example, Shackelford and colleagues (1998)
reported that men with SCI were more likely to have their spouse or parent provide support; whereas women with SCI were more likely to have a paid attendant or other relatives rather than a spouse as a caregiver. The predominance of female caregivers is likely due to the traditional gender-linked role in the family whereby women (e.g., wives and mothers) usually take on the responsibility of providing care to the family member with SCI, whereas men (e.g., husbands and fathers) play the role of the primary wage earner and are generally less directly involved in providing assistance (e.g., self-care support) to the injured individual (Khazaeipour et al., 2017; Blanes, 2005). Furthermore, the higher level of burden reported by female caregivers might also be due to the differences in the way men and women appraise and react to life in general, as women might be less reluctant to report distress than men (Holicky & Charlifue, 1999; Post, Bloemen & de Witte, 2005).

**Time Since Injury/Duration of Care**

Time since injury and duration of care provided by the family caregivers also had a direct effect on burden experienced. For example, within the first-year post-discharge, there is a learning curve for the family members to learn how to take care of the individual with SCI. Discharge from the rehabilitation centre is a crucial time in the path for the caregivers of individuals with SCI. During this time, a dual emotional state exists. On one hand, there is a need for both the individuals with SCI and their caregivers to return back home and reintegrate within the community. On the other hand, there is fear and anxiety in attempting to take on a new role and manage clinical, logistic and organizational issues (Schulz et al., 2009; Lucke et al., 2004; Marini & Reale, 2010). Furthermore, the caregivers are challenged with expectations to return to a normal situation (Conti et al., 2016). To add, most family dissolution and divorce also occurs in the first year when care demands are the highest. It is evident that, at this stage of transitioning
back home, both explicit and implicit needs arise from the family member taking on the primary role of caregiver (Conti et al., 2016). However, the burden of providing support does not end after the first year following the injury. The cumulative effects of secondary health conditions related to SCI as well as the comorbidities associated with aging, are most evident at ten years post-injury (DeVivo & Chen, 2011). Although the family caregivers have acquired the skills to provide care over the years, new health challenges associated with aging requires them to learn new skills in order to provide care (e.g. monitoring of bowel symptoms, routine medication review, and assessment of nutritional status due to the effects of neurogenic bowel dysfunction, which becomes more apparent with increasing age [Chen & Nussbaum, 2000; Correa & Rotter, 2000; Badiali et al., 1997; Stiens, Bergman & Goetz, 1997]).

2.3.1.1 Preparedness for Caregiving

Given the complexity and multifaceted nature of the caregiving role, caregivers often need to be prepared for their caregiving role. In fact, the complexity of the caregiving role has significantly increased over the years (Schulz & Eden, 2016). Traditionally, family caregivers often provided emotional support and assisted the care recipients with household and self-care activities (Schulz & Eden, 2016); however, family caregivers now need to carry out intricate medical tasks (Liem et al., 2004), organize/coordinate care tasks (Schumacher et al., 2000), provide direct care (e.g., transferring, wound care) and emotional support (Post, Bloemen & de Witte, 2005), and navigate the fragmented health care and social services systems (Schulz & Eden, 2016). Moreover, there is usually the initial distress and concern for the health condition and recovery of the family member with the disability. At the same time, caregivers may also experience challenges in trying to obtain the knowledge and skills to become competent in caring for the individuals with SCI. These skills may include bowel, bladder, and respiratory care; or
daily skin checks and recognizing the signs of a pressure injury or urinary tract infection (UTI) (National Spinal Cord Injury Association, 2011). When caregiving challenges are not addressed, this can lead to substandard symptom management, emergency hospitalizations, and unscheduled physician visits (Guilcher et al., 2013). Family caregivers require particular knowledge and skills relevant to the individual and specific needs (Dickson et al., 2010). However, one of the main contributors to burden among caregivers of individuals with SCI is the lack of resources (e.g., skills training/development) (Arango-Lasprilla et al., 2010; Archbold et al., 1990) offered to prepare caregivers for the tasks they are expected to undertake in supporting their injured relatives. It has been suggested that current rehabilitation practices do not adequately prepare caregivers for the caregiving role (Rivera, Shewchuk & Elliott, 2003). Furthermore, caregiver burden can put the care recipients’ wellbeing at risk as well. Available data suggest that individuals with physical disabilities are at higher risk to experience abuse or neglect by their family members (e.g., husbands, parents) (Milberger et al., 2003; Nosek et al., 2003) compared to individuals without disabilities (Petersilia, 2001).

2.3.1.2 Understanding Sustained Family Involvement in Caregiving

For family caregiving to be sustained, the outcome of the caregiving role needs to be positive (Baker et al., 2017). In other words, positive outcomes such as reduced adverse effects of caregiving or burden among caregivers, enhanced caregiver health and wellbeing, and optimized care for the care recipient (Revenson et al., 2016) affect sustained family involvement in the caregiving process. However, as the care recipients’ needs grow and their dependence on family caregivers increases, the caregivers’ ability to sustain their involvement in caregiving activities may be challenged. Furthermore, with the dramatic increase in the incidence of NTSCI anticipated over the coming two decades as a result of the aging population across Canada (Farry
& Baxter, 2010), this nation might be facing a looming care gap. Finding ways to support family caregivers will continue to be a critical public health focus.

### 2.4 Existing Interventions to Support Caregivers of Individuals with SCI

A number of interventions have been developed to optimize outcomes for family caregivers and the care recipients with SCI. The following section reviews the evidence on interventions directed at supporting family caregivers of individuals with SCI, including the content of the interventions, their efficacy and effectiveness, and limitations.

A review of literature revealed four randomized controlled trials (RCT) and one quasi-experimental research (pretest-posttest design) which examined the efficacy and effectiveness of interventions aimed to support caregivers of individuals with SCI (Table 2.1). Interventions include video conferencing and face-to-face problem-solving training (PST) (Rivera, Shewchuk & Elliott, 2003; Elliott & Berry, 2009), psycho-educational interventions (Molazem et al., 2014; Schulz et al., 2009), and peer support (Sheija & Manigandan, 2005).

The first RCT conducted by Rivera and colleagues (2003) examined the effectiveness of an individualized PST intervention delivered via videoconferencing with family caregivers of individuals with SCI. Sixty-seven family caregivers were randomly assigned to either an educational-only control group or an intervention group in which participants received PST in monthly videoconference sessions for a year. PST was used to help family caregivers to negotiate the practical demands of providing assistance to an individual with SCI. For example, caregivers were trained to create solutions to commonly encountered caregiving challenges (e.g., transferring from wheelchair into a vehicle), and generate alternative solutions (e.g., hoist, manual assist, sliding board) to meet their needs. Caregivers who received PST showed a significant decrease in depression (p < 0.05) in comparison to the control group at 6 months post-
intervention. Also, caregivers receiving PST reported significant improvement in social functioning (p < 0.05) over time.

Similarly, another RCT conducted by Elliot and Berry (2009) also explored the effectiveness of PST, particularly brief individualized PST, on caregivers of individuals with recent onset SCI. Sixty caregivers were randomly assigned to either the intervention group receiving face-to-face PST (along with educational materials and telephone contacts), or the usual care control group (usual access to outpatient rehabilitation professionals and information on SCI management). The caregivers who received PST reported a significant decrease in dysfunctional problem-solving styles scores after one year, as well as beneficial effects on caregiver social and physical functioning. However, there were no observable effects for PST on caregiver depression.

A more recent RCT by Molazem and colleagues (2014) investigated the effectiveness of psycho-educational interventions on the quality of life of family caregivers of individuals with SCI. Sixty-two caregivers were randomly divided into either the intervention group who received weekly educational sessions (e.g., coping strategies, appropriate care provision to care recipients, crisis confrontation strategies, etc.), or the usual care control group (did not receive educational sessions). Post-intervention, the quality of life (including physical function, role physical, bodily pain, general health, vitality, social function, role emotional and mental health) had improved in the caregivers who were assigned to the intervention group compared to the control group (p < 0.05).

Schulz and colleagues (2009) conducted an RCT to assess the efficacy of two psychosocial problem-solving interventions for caregivers of individuals with SCI on measures of depressive symptoms, burden, social support and integration, self-care problems, and physical
health symptoms. One hundred seventy-three caregiver and care recipient dyads were randomly assigned to one of the three groups: 1) a caregiver-only intervention group in which caregivers received a multicomponent intervention (e.g., received knowledge and cognitive/behavioural skills to reduce stress, improve health and self-care, enhance access to formal and informal support, etc.) based on their risk profile; 2) a dual-target group in which the caregiver intervention was accompanied by a treatment targeting the care recipient (designed to address both caregiver and care recipient risk factors); and 3) information-only control group in which the caregiver received standard written information about SCI, community programs and resources, caregiving and aging. Caregivers in the dual-target condition group reported improved quality of life (improvement of at least 0.5 SD from baseline to follow-up), significantly fewer health symptoms, and were less depressed when compared to the caregiver-only and information-only control condition groups at 12 months post-intervention.

Finally, a pretest-posttest study by Sheija and Manigandan (2005) explored the efficacy of outpatient support groups for caregivers of individuals with SCI and their impact on quality of life. Thirty-six caregivers (spouses) were stratified into either a support group or a control group. The support group met three times weekly to have discussions about the previous session’s home tasks (e.g., difficulties encountered completing household tasks), engage in topic specific performance (e.g., role plays, situational analysis), as well as receive situation-specific home tasks to practice and improve problem-solving among caregivers. A post-evaluation was conducted following seven support group sessions for the support group and after 2 weeks of pre-assessment for the control group (who did not receive any support). The support group was determined to be effective in improving caregivers’ general health (p = 0.003) and quality of life (p = 0.001) and reducing psychological distress (p = 0.001) in comparison to the control group.
<table>
<thead>
<tr>
<th>Author (year), Country</th>
<th>Study Design, Population (n), Participant characteristics</th>
<th>Intervention description</th>
<th>Results</th>
</tr>
</thead>
</table>
| Rivera et al. (2003) USA | * RCT  
Family caregivers (n= 67)  
Experiment group (n= 33): 4 men, 29 women; average age, 51.3y  
Education-only control group (n= 34): 34 women; average age, 50.8y | * Individualized PST intervention delivered via videoconferencing  
Videoconferences held monthly for 1 year  
Training of problem solving techniques consisting of: 1) defining problem; 2) achieving positive frame of mind; 3) generating potential solutions; 4) implementing solution; 5) evaluating results | Intervention group showed significant decrease in depression (p < 0.05) compared to control group at 6 months post-intervention  
Intervention group showed significant improvement in social functioning (p < 0.05) over time |
| Elliott & Berry (2009) USA | * RCT  
Family caregivers (n= 60)  
Experiment group (n= 30): 3 men, 27 women; average age, 42.1y  
Usual care control group (n= 30): 8 men, 22 women; average age, 43.3y | * Brief individualized PST, on caregivers of individuals with recent onset SCI  
3 face-to-face PST sessions, educational materials and telephone contacts during first year of caregiving  
Training of problem-solving process: 1) defining problem; 2) being optimistic; 3) creativity/generating alternatives; 4) understanding and decision-making; 5) solving problem including implementing and evaluating solution | Intervention group showed significant decrease in dysfunctional problem-solving styles scores after one year, as  
Intervention group reported beneficial effects on caregiver social and physical functioning  
No observable effects for PST on caregiver depression |
| Molazem et al. (2014) Iran | * RCT  
Family caregivers (n= 62)  
Experiment group (n= 33): 2 men, 31 women; average age, 44.1y  
Usual care control group (n= 29): 1 man, 28 women; average age, 44.8y | * Psychoeducational intervention on caregivers via face-to-face, group education, discussion and lecture  
90-minute educational sessions held once a week for 4 weeks  
Training in: 1) coping with stress and depression; 2) relaxation techniques; 3) crisis confrontation strategies; 4) strategies to provide care recipient with appropriate physical care | Intervention group reported improved quality of life (e.g., general health, physical function, role physical, vitality, bodily pain, social function, role emotional and mental health) compared to control group (p < 0.05) |
| Schulz et al. (2009) USA | * RCT  
Family caregivers (n= 173); care recipients (n= 173)  
Caregiver-only experiment group (n= 56): 14 men, 42 women; average age, 53.7y  
Dual-target experiment group (n= 57): 9 men, 48 women; average age, 50.7y | * Psychosocial problem-solving for caregivers of older SCI individuals  
Caregiver-only intervention group:  
received knowledge and cognitive/behavioural skills to reduce stress, enhance access to formal and informal support, improve emotional well-being, improve health and self-care  
consisted of seven 60-90 min individual sessions delivered over 6 months at home or by | Caregivers in dual-target condition group reported improved quality of life compared to control group  
Dyads in dual-target condition group reported significantly fewer health symptoms compared to caregiver-only group and control group  
Dyads in dual-target group reported significant improvement in burden and depression compared to caregiver-only group |
2.4.1 Limitations of Existing Interventions and Intervention Studies

Despite the fact that several intervention studies found positive results, the quality of evidence (due to the methods of evaluating the interventions) was generally low (Smith et al., 2016). For example, these interventions showed that the evaluation often consisted of multiple primary and secondary outcomes (Elliott et al., 2008; Elliott & Berry, 2009; Molazem et al., 2014; Schulz et al., 2009; Sheija & Manigandan, 2005). As a result, all interventions had a positive outcome/effect on at least one of the outcome measures. Therefore, having multiple interrelated outcome measures might lead to spurious findings (Revenson et al., 2016). Second, the significant effects of the interventions tested in RCTs are more likely to be found when the experimental or intervention groups are compared with wait list control groups, instead of the active usual care control group that was receiving at least minimal education and informational support (Lawang et al., 2013; Corry et al., 2015). For example, wait list control groups provide
an untreated comparison for the experimental groups to determine if the intervention had an effect. By serving as a comparison group, researchers can segregate the independent variable (i.e., the intervention) and observe the impact it had on the caregivers (Schimelpfenning, 2017). However, none of the intervention studies reviewed above consisted of the untreated wait list control groups. Instead, all studies had the usual care control groups who received standard information/education; thus, creating specious findings on the effectiveness of the interventions.

In addition, there were some limitations in the interventions themselves. It is important to note that caregivers experience various caregiving challenges that may shift over time (particularly over 10 years post-injury), a consideration that none of the interventions addressed (resulting in a notable limitation to the interventions). Also, the available intervention studies in the literature are within a time span of approximately 10 years (2005-2014), with the most recent intervention conducted 4 years ago. Thus, these studies may not be representative of the current scope of caregiving in SCI (Smith et al., 2016). Finally, to date, there has not been any caregiver intervention studies conducted within the SCI population in Canada. Given the increasing costs and potential burden associated with caregiving for individuals with SCI in Canada (Krueger et al., 2013), this represents a considerable gap in the literature that needs to be addressed.

The development of high-quality interventions that aim to alleviate the negative impact of caring on caregivers of individuals with SCI while improving patient outcomes is warranted. However, one of the reasons for the inconsistency in these findings is that the majority of interventions have been developed without a clear understanding of caregivers’ needs (Robinson et al., 2005). For example, there is a lack of knowledge on the content and delivery of interventions based on caregivers’ needs. The current study contributes new knowledge (e.g.,
current support care needs of SCI family caregivers) that could be used to inform intervention development within a Canadian setting.

2.5 Unmet Supportive Care Needs of Family Caregivers of Individuals with Spinal Cord Injury

Family caregivers make an important contribution to the care processes and overall quality of life of individuals with SCI; it is no surprise, then, that these caregivers have particular needs that must be met in order to ensure successful rehabilitation of the individual with SCI (Arango-Lasprilla et al., 2010; Stanton, 1984). However, little empirical information is available to characterize the needs of SCI caregivers, with more research studies focusing on the needs of the individual with SCI (Arango-Lasprilla et al., 2010). Despite this, a few studies found frequently reported needs of SCI family caregivers.

An early study by Hart (1981) examined the needs of seven spouses within 5 to 40 days post-injury. A qualitative method was used to identify the following needs: feeling adequately informed, being able to cope with home and family responsibilities, feeling helpful to the care recipient, receiving emotional support, being able to express feelings, believing that patient care is adequate, and helping deal with concerns regarding the future impact of the injury. The findings suggested that needs for realistic information related to the care recipient’s condition and prognosis, emotional support, and assurance concerning quality of care were commonly reported by the caregivers.

Another early study by Stanton (1984) examined the needs of ten family members in a hospital setting 4 to 24 weeks post-injury. Using a 24-item needs assessment questionnaire, the participants rated needs related to communication with health care professionals as most
important. Specific needs that were emphasized as important to caregivers included acceptance by rehabilitation personnel; reassurance from the staff; informed and honest communication about patients’ treatment, care and progress; and knowing the available resources within the hospital. In addition, the need to visit the patient whenever and the need for someone to communicate with were rated as important or very important by the majority of participants. Stanton emphasized the significance of consistent monitoring of family needs within the rehabilitation setting so as to facilitate treatment and discharge planning.

More recently, a cross-sectional quantitative study by Arango-Lasprilla and colleagues (2010) examined the frequent needs and psychosocial functioning in a group of family caregivers (n = 37) of individuals with SCI in South America. Using a caregiver needs questionnaire, thirty-seven caregivers rank-ordered their needs (based on the categories in the questionnaire). The most frequently reported needs included information, economic, emotional, community support, and respite care. The results further demonstrated that family needs were associated with depression, burden, social support, and life satisfaction. The authors concluded that further research is warranted to address the needs of family caregivers of individuals with SCI in order to improve their psychosocial functioning.

Although prior SCI studies have provided some insight into family support needs, they were a secondary focus of investigation. There is a paucity of studies exploring caregivers’ needs directly related to the care and support provided to the individuals with SCI. In addition, the majority of studies had relatively small sample sizes. Although Arango-Lasprilla and colleagues (2010) studied the largest sample, they did so using a generic questionnaire that did not address other important caregiver needs (e.g., professional or instrumental needs). Furthermore, existing SCI studies explored the needs of caregivers who were predominantly from the United States.
Caregiver support needs may, in fact, vary between country of origin as a result of different health and social care systems (Arango-Lasprilla et al., 2010).

2.6 Summary and Study Rationale

To a great extent, family caregivers of individuals with SCI currently operate as an integral component of the healthcare system. However, with decreased lengths of stay in hospitals and reduced health care budgets, more responsibility will fall to the family caregivers who are generally unprepared and unsupported to assume the caregiving role (Elliott, Shewchuk & Richards, 1999). In fact, one of the main contributors to burden among caregivers of individuals with SCI is the lack of resources (e.g., skills training/development) (Arango-Lasprilla et al., 2010; Archbold et al., 1990) provided to prepare caregivers for the tasks they are expected to undertake. Consequently, this can lead to substandard symptom management, emergency hospitalizations, unscheduled physician visits, and emotional pain for both the individuals with SCI and family caregivers (Guilcher et al., 2013). Rehabilitation professionals concur that family caregivers play a vital role in the rehabilitation of the individuals with SCI, and that attention to their needs results in enhanced care recipient outcomes (Arango-Lasprilla et al., 2010; Stanton, 1984). Yet, surprisingly little is known about the support needs of SCI caregivers. The enclosed review of the literature has highlighted that some early research has focused on family needs of individuals with SCI; however, they were a secondary focus of investigation and not directly related to the care and support provided to the individuals with SCI. Furthermore, empirical evidence is limited in scope and does not reflect the changing needs of the caregivers over time. Finally, there are no studies exploring SCI caregiver support needs within a Canadian context. Thus, we need to think proactively, and with a long-term perspective in considering ways to ensure sustainability of these critical supports. Currently, there are gaps in our understanding of
the support needs associated with the facilitators and barriers in providing care; care recipient factors that influence the support needs of family caregivers; and the skills needed to enhance competency in caring for individuals with SCI. Together, these findings suggest a more in-depth investigation of support needs of family caregivers of individuals with SCI is needed. The knowledge gained from this research can be used to enhance support for family caregivers, including the development of evidence-informed interventions that can promote sustained family involvement in the caregiving process and improve the health and wellbeing for both individuals with SCI and their family caregivers.

2.7 Research Goal and Specific Objectives

The overall goal is to contribute an in-depth understanding of the caregiving experiences and associated family caregiver support needs in providing care to individuals with SCI within 2 years and after 10 years post-discharge from inpatient rehabilitation. It is assumed that family caregivers will have unique needs in providing care to individuals with SCI; and this insight can facilitate the future development and implementation of support services/programs to promote sustained family involvement in the caregiving process.

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

1. To determine the perceived facilitators and barriers to undertaking and sustaining the caregiving role in the community;

2. To determine the types of support needed by individuals with SCI post-discharge from inpatient rehabilitation, and the factors associated with the need for more support;

3. To determine the breadth of skills needed by family caregivers to enhance competency in caregiving of individuals with SCI; and
4. To have a greater understanding of how caregivers and care recipients negotiate changes within the relationship post-SCI
Chapter 3
Overview of Methods

3.1 Chapter Overview

This chapter provides an overview of the research methods used in the thesis. The specific details of the methods used can be found in the individual papers in chapters four to seven.

3.2 Overview of Research Design

This research used a qualitative descriptive approach with an exploratory design to address the research objectives (Sandelowski & Barroso, 2003; Sandelowski, 2010). Qualitative research can provide insights about a phenomenon that has rarely been studied (i.e., SCI family caregiving needs), address gaps in our understanding, provide a new perspective on a situation (Schreiber, 2001), as well as contribute to our overall understanding of the lived experiences of family caregivers and care recipients (Creswell et al., 2003). In addition, qualitative research findings are a credible source of research evidence for public health practice (Upshur, 2001; Jack, 2006), including intervention research (Gilgun & Sands, 2012). Research ethics approval was obtained from the University Health Network and the University of Toronto (Please see Appendix A for the Research Ethics Board approvals).

3.3 Positionality

Throughout the research process, I tried to recognize my positionality as a researcher and how that empowers or constrains my role as a co-producer of participants’ accounts. I recognized that my attributes, beliefs, demeanor, demographic characteristics (South Asian,
university-educated, female in her early thirties), as well as the questions I asked during the interviews influenced what participants chose to speak about, what they felt uncomfortable sharing, and how they presented themselves. I was also aware that my experience in health services research impacted me to recognize certain aspects of participants’ accounts. This awareness enabled me to call into question some of my own assumptions and expectations throughout the research process. To ensure reflexivity, I wrote extensive memos consisting of my reflections, observations and thoughts during the interviews, as well as during the development of categories and themes. My thesis committee also helped to promote reflexivity by reviewing a subset of the transcripts, asking thought-provoking questions, and discussing alternate interpretations of the findings during committee meetings.

3.4 Conceptualization of the Study: The Knowledge-to-Action Framework

Key processes of the Knowledge-to-Action (KTA) framework (Graham et al., 2006) were used to guide the overarching conceptualization of the study. Developed by Graham and colleagues, this framework incorporates components of over 30 planned action theories that represent phases of activities required for knowledge applications to achieve an effective change in certain settings and groups of individuals (e.g., community or healthcare organizations/professionals). For example, the knowledge gained from the current study could be used to inform clinical practice guidelines or evidence-based programs to support caregivers of individuals with SCI. The KTA framework has been adopted as the accepted model for promoting the application of research and knowledge translation by the Canadian Institutes of Health Research.

The KTA framework is composed of two distinct, but related components: (i) Knowledge Creation; and (ii) the Action Cycle (Figure 3.1). The knowledge-to-action process is iterative and
dynamic, whereby the components of knowledge creation and action cycle can move between each other, in an iterative fashion.

3.4.1 Knowledge Creation

The first component of the KTA framework is the knowledge creation, or ‘knowledge funnel’, which illustrates the production and synthesis of knowledge. Knowledge creation is composed of three phases: knowledge inquiry, knowledge synthesis, and creation of knowledge tools and products (Graham et al., 2006). As knowledge moves through the funnel of the knowledge creation process, the resulting knowledge is refined, summarized and tailored to the needs of end-users (e.g., healthcare professionals and policy makers) (Straus et al., 2011). First, knowledge inquiry refers to primary studies that could be used to inform future research and contribute to the larger evidence base. Second, knowledge synthesis represents the aggregation of existing knowledge (i.e., synthesis of findings from individual research studies) and interpreting them within the context of global evidence. Finally, the creation of knowledge tools and products involves synthesized knowledge to present evidence in refined and user-friendly formats (e.g., practice guidelines or patient decision aids) tailored to meet end-user needs (Straus et al., 2011). The current research focuses solely on the phases related to the Knowledge Creation component of the KTA framework.

3.4.2 The Action Cycle

The action cycle is the process by which knowledge is implemented. The action cycle of the KTA framework includes phases of activities (based on planned-action theories) that are required for knowledge applications to achieve a deliberately engineered change in groups and healthcare settings (Graham et al., 2007; Straus et al., 2011). The action phases may be carried
out sequentially or simultaneously; and the knowledge creation phases can influence the action phases at any point (Graham et al., 2005). The seven phases of the Action Cycle include: identifying the problem (i.e., identify, review, select knowledge); adapting knowledge to local context; assessing barriers/facilitators to knowledge use; selecting, tailoring, implementing interventions; monitoring knowledge use; evaluating outcomes; and sustaining knowledge use (Straus et al., 2011).

![Figure 3.1: Knowledge-to-Action Framework](image)

Figure 3.1: Knowledge-to-Action Framework
3.5 Approach to Participant Recruitment

The following sub-sections will discuss the approach used for participant recruitment in the current study, including sampling strategy, eligibility criteria, and recruitment sites and strategies used in the current study.

3.5.1 Sampling Strategy

Purposive sampling by time since discharge and caregiver relationship was used to select and recruit the participants for the study. First, taking into account the learning curve that occurs within the first two years, as well as the evolving needs required by individuals with SCI and family caregivers over time (Schulz et al., 2009; Lucke et al., 2004; Marini & Reale, 2010; DeVivo & Chen, 2011), participants (i.e., individuals with SCI or family caregivers) who were (or have been providing care to an individual who was) at least 3 months to up to 2 years post-discharge from inpatient rehabilitation, and after 10 years post-discharge were recruited. Second, given the dynamics of relationships as well as the roles and expectations in providing care varies according to different family relationship, participants were also recruited based on caregiver relationship to the care recipient (i.e., spouses and parents). Specifically, spouses and parents were recruited in the study because family caregivers of individuals with SCI are most often spouses and parents (Ellenbogen et al., 2006).

3.5.2 Eligibility Criteria

Given the potentially important synergistic effects of caregiving whereby caregivers and care recipients mutually affect each other (Schulz et al., 2009), this study addressed its objectives by including both the individuals with SCI and family caregivers, either as dyads (i.e., caregivers...
and care recipients from the same family) or individually (either the caregiver or care recipient within a family).

3.5.2.1 Eligibility Criteria for Individuals with Spinal Cord Injury

The individuals with SCI who were eligible to participate in the study included: 1) being at least 18 years of age; 2) having experienced either traumatic (e.g., fall, sporting accident, motor vehicle accident) or non-traumatic (e.g., cancer, inflammation, disc degeneration of spine, arthritis) SCI; 3) having a SCI (paraplegia or tetraplegia) with a complete or incomplete lesion; 4) being 3 months and up to 2 years post-discharge or after 10 years post-discharge from inpatient rehabilitation; and 5) being fluent in English.

3.5.2.2 Eligibility Criteria for Family Caregivers

Family caregivers were recruited through the individuals with SCI and were identified as his/her primary caregiver. Family caregivers who were eligible to participate in the study included: 1) being a spouse or parent of an individual with SCI; 2) described themselves as providing physical (e.g., instrumental) and/or psychological (e.g., emotional) support to the individual with SCI; 3) having regular contact with the individual with SCI (i.e., face-to-face at least weekly); and 4) being fluent in English.

3.5.3 Recruitment Sites and Strategies

Individuals with SCI who are living in the community across Canada and their family caregivers were recruited from: 1) participants in the Rick Hansen Institute (RHI) SCI Community Survey (RHISCICS); 2) the Toronto Rehabilitation Institution (TRI)- Lyndhurst Centre outpatient clinic; and 3) Spinal Cord Injury Ontario (SCIO).
**Rick Hansen Institute SCI Community Survey**

The RHISCICS is a collaborative research study sponsored by the RHI, a major organization within Canada that tracks the experiences and outcomes of people with SCI living in the community. A list of individuals with SCI from the RHISCICS who had previously agreed to be contacted for research purposes were invited to participate in the study. An initial email with the letter of invitation and consent form to participate in the study were sent out by a recruiting officer from the RHI to all individuals who consented to be contacted. Please see Appendices B and C for the letter of invitation and consent form. Individuals (i.e., individuals with SCI and/or their self-identified family caregivers) who responded with an interest to learn more about the study were then contacted by myself (primary author) to provide further details regarding the study and check for eligibility to participate. Participant availability for telephone interview was also confirmed. If a response email was not sent back within two weeks, a follow-up email was sent out to the individuals who had not responded.

**Toronto Rehabilitation Institute**

TRI-Lyndhurst Centre has the largest outpatient SCI clinic in Canada. A member of the healthcare team at the centre provided the individuals with SCI and their caregivers the letter of invitation and consent form to participate in the study. The healthcare professional completed a standardized patient referral form that gave consent for the primary author to approach interested individuals with the study details. Please see Appendices D and E for the patient referral forms for the individuals with SCI (patients) and family members/caregivers respectively. Participant eligibility and availability for in-person (at the clinic) or telephone interview was also confirmed.
Spinal Cord Injury Ontario

SCIO, consisting of 16 offices across the province, is a community-based service provider to individuals living with SCI within Ontario. An online advertisement was posted on the SCIO web site to recruit participants (Please see Appendix F for the flyer). Individuals who responded with an interest to learn more about the study were contacted by the primary author to provide further details of the study and check for eligibility to participate. Eligible individuals who were interested in participating in the study received the consent form. Participant availability for telephone interview was also confirmed.

3.6 Approach to Data Collection

Semi-structured telephone or in-person interviews were conducted with the individuals with SCI and family caregivers by the primary author. Some researchers have implied that the use of telephone could undermine the quality of data in qualitative research (Opdenakker, 2006; Sturges & Hanrahan, 2004; Sweet, 2002) particularly due to the absence of visual cues, which can result in the loss of informal communication and contextual information, the inability to develop rapport or to probe, and the misinterpretation of responses (Creswell, 1998; Opdenakker, 2006). However, due to the national scale of this study as well as the possible limitations associated with accessibility, telephone interviews were also conducted. Furthermore, telephone interviews may allow the participants to share their lived experiences, or rather disclose any sensitive information, more freely as this method permits more anonymity (Tausig & Freeman, 1988; Sweet, 2002) and privacy (Sturges & Hanrahan, 2004), and decreases social pressure (McCoyd & Kerson, 2006).
At the time of the interview, the primary author outlined the details of the study and consent form, as well as answered any questions (please see Appendix G for the oral consent script). Participants were asked to provide verbal consent at the time of the interview. The consent form was also signed and dated by the primary author who obtained the participant’s verbal consent to study participation. All participants agreed to have the interviews audio-recorded. Recruitment ceased as the study approached the point of data saturation, where successive interviews became repetitive and no new responses or themes emerged (Creswell et al., 2003).

The interview guides for both the care recipients and caregivers consisted of semi-structured open-ended questions; and were pilot tested with one of the authors experienced in qualitative methods as well as an individual with SCI and his caregiver. The interview guides were developed using the grey and published literatures, and in accordance with the Theoretical Domains Framework (TDF, discussed below).

3.6.1 Development of Study Interview Guides Using Theory: The Theoretical Domains Framework

Implementation science fosters the systematic uptake of research findings into clinical practice with the objective to enhance patient care and healthcare outcomes (Phillips et al., 2014). However, implementing new practices and/or changing existing practices in organizations, services and systems require changes in individual as well as collective behaviour (Atikins et al., 2017). Particularly, the success of implementation efforts (e.g., evidence-based programs) is contingent on a careful assessment of certain factors, such as barriers and enablers (Phillips et al., 2014).
The TDF, developed by Michie and colleagues (2005) in an integrative framework that comprises of 14 domains and 84 constructs that could be used to inform the design of appropriately targeted interventions (e.g., caregiver support programs). A key aspect of the proposed objectives of the current study involves embedding the TDF within the KTA framework to guide the effective development of evidence-based programs to support family caregivers of individuals with SCI in the future. For example, examining the facilitators and barriers to providing care to individuals with SCI using the TDF can help identify modifiable factors that can be used to develop theoretically informed interventions to support families in undertaking and sustaining the caregiving role.

A recommended interview guide for the TDF, developed by Michie and colleagues (2005), was used as a guideline in creating the interview questions for the current study. Specifically, interview guides were based on certain TDF domains that are most relevant to addressing SCI family caregiver needs that could be used to facilitate implementation of supports for caregivers. These included: (1) knowledge (i.e., knowledge about the injury through training and information); (2) skills (i.e., skills needed to take care of the individual with SCI); (3) beliefs about capabilities (i.e., facilitators/capability to take care of the individual with SCI); (4) beliefs about consequences (i.e., barriers towards taking care of the individual with SCI and obtaining skills needed); (5) environmental context (i.e., availability and accessibility of necessary resources for caregivers to provide care); (6) social influences (i.e., availability of support system, such as peer support groups); and (7) emotion (i.e., emotional factors related to caregiving, such as stress, fear, burnout). Please see Appendices H & I for the caregiver and care recipient interview guides, respectively.
3.7 Approach to Data Analysis

Data collection and analysis were carried out in an iterative manner. The accuracy of the transcribed data was verified by the primary author by cross-checking several transcripts. All identifying information was removed from transcripts prior to being reviewed by the other research team members. NVivo 10 (Castleberry, 2012) was used to organize data and support analysis. The following provides an overview of the data analysis procedures used in the study. The specific data analysis methods can be found in the individual papers in chapters four to seven. Qualitative content analysis was used to analyze the data pertaining to chapter five as the purpose of this manuscript was to categorize the types of support needed. Chapters four, six and seven used qualitative thematic analysis procedures to analyze the data in an effort to understand the lived experience of caregivers and care recipients.

3.7.1 Qualitative Content Analysis

Using a qualitative content analysis approach (chapter five), as described by Hsieh and Shannon (2005), data were analyzed in a 2-stage process: 1) an inductive approach to determine the types of support needed; and 2) a summative approach to determine the frequency of types of support within the various factors associated with the need for more support. Detailed descriptions of the qualitative content analysis procedure are presented in chapter five.

3.7.2 Qualitative Thematic Analysis

Qualitative thematic analysis was performed to code and analyze the data for chapters five to seven. Data analysis was stratified based on the time since discharge and caregiver relationship. The process of analysis was guided by the adaptation of Braun and Clarke (2006) inductive thematic analysis process, detailed below. The six phases of analysis include: 1)
familiarizing yourself with your data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report (Braun & Clarke, 2006).

1) **Familiarizing yourself with your data:** each transcript was read thoroughly several times as a whole so as to become familiarized with the data and make preliminary observations.

2) **Generating initial codes:** Beginning with open coding, a subset of the transcripts was initially coded and excerpts (i.e., key phrases and words) of the transcripts that described the responses based on meaning that emerges from the data were highlighted and written in the margin of the transcripts. Similarities and relationships between the chosen key phrases and words were identified and combined so as to strengthen data groupings (i.e., axial coding). As this process continued, labels for codes emerged that are reflective of more than one key thought. For example, if the participants consistently mentioned wound care, bowel/bladder management, etc. as a perceived skill needed, then these key phrases/words formed the open codes. These open codes were then used to form an axial code (e.g., symptom management skill need). This process assisted in the categorization of the codes. A codebook (consisting of all emerging codes, definitions and examples) was created to organize all codes and to help analyze data. Please see Appendix J for the codebook. In addition, the codes between caregivers and care recipients were mapped along the time of the recovery trajectory to get an idea of the parallel progression between the family caregiver and the recipient’s experience. By doing so, this helped in the identification of overlapping and contrasting data between the caregivers and recipients. This also ensured a global perspective that is more than the sum of the individual versions.

3) **Searching for themes:** Codes identified in the previous step were sorted into potential overarching themes. For example, the following criteria were used to group skills into broader
categories that signify varying SCI family caregiving processes: similarities/differences, thematic overlaps, and redundancy of coded data.

4) **Reviewing themes:** This phase involved two levels of reviewing and refining the themes. Level one involved reviewing the collated extracts for each theme and confirming whether they appeared to have formed a coherent pattern. Level two involved confirming whether the validity of individual themes was related to the data set. This phase further involved re-coding and re-naming themes. New codes were integrated into the codebook as the analysis progressed and applied by the first author to the remaining transcripts.

5) **Defining and naming themes:** The themes were then defined and further refined. For example, this phase involved determining the essence of what each theme implies (i.e., what feature of the data each theme captures). From this process, various thematic maps were explored until consensus was reached and theme labels were agreed upon.

6) **Producing the report:** The final phase involved explaining the data (within and across themes) in a concise, logical and coherent manner. Also, participant quotations were included in the final report to exemplify the themes as well connect them to the data.

The analysis procedure was systematic such that there was a standardized thematic process, including a systematic coding scheme, that was used to identify and sort meaning units as well as condensing and synthesizing into meaningful themes. This process ensured reflexivity, intersubjectivity, and feasibility, as well as methodological rigor. Independent, duplicate coding by multiple team members further ensured rigor and validated the integrity of the coding process. This process of thematic analysis was appropriate to address the study’s objectives because the overall caregiver/care recipient experiences were condensed into important themes/concepts.
related to the various support needs of family caregivers in providing care to individuals with SCI.
Chapter 4
Facilitators and Barriers to Supporting Individuals with Spinal Cord Injury in the Community: Experiences of Family Caregivers and Care Recipients

Abstract

Purpose: Family members make an important contribution to the informal and formal care, as well as the overall health and wellbeing of individuals with spinal cord injury (SCI). Caregiving often results in negative outcomes which, if not addressed, threatens the sustainability of these critical supports. We sought to explore the perceptions of individuals with SCI and their family caregivers regarding the facilitators and barriers to undertaking and sustaining the caregiving role in the community.

Methods: A qualitative descriptive approach with semi-structured interviews was used. Thematic analysis was employed to determine key themes arising from individuals with SCI’s (n=19) and their family members’ (n=15) experiences.

Results: The following four facilitators to caregiving were identified: access to community support services, positive coping in relationship, social support, and mastery of caregiving roles. Conversely, the following six barriers to caregiving were identified: lack of access to community resources, lack of knowledge about resources and formal training, fragmented continuity of care, negative coping in relationship, role strain, and caregiver injury or illness.

Conclusions: The current study demonstrated that positive coping, social support, skills training, access to community services, and continuity of care contribute significantly to the sustainability of the SCI family caregiving role. As such, the development of future caregiver interventions should incorporate these considerations.
4.1 Introduction

Spinal cord injury (SCI) causes profound changes in nearly all of the body systems and an individual’s functional abilities, usually of sudden onset and of an unexpected nature (e.g., motor vehicle collisions, falls, etc.). Without an opportunity for preparation, the individuals with SCI, their family and social network undergo the process of adjustment to meet their care needs following injury onset. In the past, individuals with SCI often stayed in rehabilitation centres for approximately six months to a year (Crewe & Krause, 2009), and this allowed time for gradual adjustment to the physical and psychological changes after the injury. Currently, the decreased length-of-stay in tertiary SCI rehabilitation centres in North America (Whiteneck et al., 2011) has led to individuals entering the community without obtaining sufficient knowledge and self-management skills to support their independence (McColl et al., 2012). Thus, many individuals rely heavily on family members and friends for support with an array of services, some of which were formerly provided by regulated healthcare professionals (Schulz et al., 2009).

Much like individuals with SCI, family caregivers also experience adjustment challenges; whereby, they are required to reconstruct their lives and start an “unexpected career” in order to provide assistance with activities of daily living (ADLs), personal care, and emotional support, to their family member with a disability (Archbold et al., 1990; Dickson et al., 2010). Given the numerous roles that family members undertake in the care and support of individuals with SCI, there is an increase in negative caregiver outcomes (e.g., distress, strain, burnout, etc.), which threatens the sustainability of these critical supports if the caregivers’ needs are not addressed accordingly. Various studies have documented the negative effects of caring for an individual with SCI (Charlifue et al., 2016; Gajraj-Singh et al., 2011; Dickson et al., 2010). Caregiver burden can result in role overload (i.e., inability to balance ongoing demands of caregiving, as
well as personal obligations) (Charlifue et al., 2016), loss of self due to the caregiver role (Thoits, 1995), or even neglect of personal health. Weitzenkamp et al. (1997) reported that spouses of individuals with SCI for greater than 23 years, who assumed the role of caregiver, had higher levels of stress, fatigue, burnout, resentment and depression in comparison to spouses who were not caregivers. Several authors have reported higher self-reported levels of psychological distress in caregivers of individuals with SCI compared to individuals with SCI (Weitzenkamp et al., 1997; Robinson-Whelen & Rintala, 2003; Chan, 2000). Furthermore, caregivers of individuals with SCI may be at greater risk of burnout, in comparison to caregivers of individuals living with other chronic illnesses and injuries, due to the unique challenges of providing care related to the complications tied to SCI (e.g., bladder and bowel problems, and pressure injury management [Nogueira et al., 2012], and the longer duration of their caregiving period [Schulz et al., 2009]).

Considering the increasing need for family members to provide intensive, long-term care for their injured relative (Charlifue et al., 2016), researchers have started examining the wide range of factors related to caregiver burden. A study by Post, Bloemen, and de Witte (2005) reported that the number of hours spent on providing ADL support was the most significant predictor for caregiver burden. Other important determinants included the number of psychological problems of the individual with SCI, the age of the caregiver (caregiver burden increases with age), and the overall length of caregiving (caregiver burden decreased with duration of care (years). LaVela and colleagues (2015) compared outcomes among caregivers of individuals with SCI to caregivers of individuals with other neurological conditions. The authors found that inadequate sleep quality and duration are more common among caregivers of
individuals with SCI compared to other neurological conditions due to the specific round-the-clock assistance with bladder, bowel and skin care (e.g., repositioning) (LaVela et al., 2015).

While the above research has raised awareness of the negative effects of caregiving and the factors associated with caregiver burden, there are several gaps within the literature. The majority of SCI caregiver studies have reported negative outcomes as a result of caregiving; but, the barriers, and particularly, the facilitators to providing care have not been established (Baker et al., 2017). Not only do we have limited knowledge about the factors that facilitate the transitions back into the community, we have limited to no understanding of the factors that hinder or support family members acting as caregivers in the long-term. Given that the family caregiver plays a vital role in sustaining the care recipient’s overall health and wellbeing, understanding the caregiver experiences, factors that facilitate caregiving, and challenges faced in undertaking and maintaining the role, can help identify possible strategies to promote sustainable family caregiving, and potentially improve the caregiver and care recipient’s overall quality of life. Thus, the purpose of the current study was to explore the perceptions of individuals with SCI and their family caregivers regarding the facilitators and barriers to undertaking and sustaining the caregiving role in the community and to suggest strategies for improvement.

4.2 Methods

4.2.1 Design

A qualitative descriptive study was undertaken (Sandelowski & Barroso, 2003; Sandelowski, 2010). A qualitative approach will contribute to our understanding of the lived experiences of caregivers and care recipients related to providing and sustaining care. Given the
potentially important and synergistic effects of caregiving whereby caregivers and care recipients mutually affect each other (Schulz et al., 2009), this study included both the individuals with SCI and their family caregivers. Research ethics approval was obtained from the University Health Network and the University of Toronto.

4.2.2 Participants and Recruitment

Individuals with SCI who are living in the community across Canada and their family caregivers were recruited from a list of participants from the Rick Hansen Institute (RHI) SCI Community Survey (RHISCICS); Spinal Cord Injury Ontario (SCIO)- a community-based service provider to individuals with SCI; and a large outpatient SCI clinic. Participants were recruited through: i) a letter of invitation sent via e-mail from a list of individuals from the RHISCICS who had previously agreed to be contacted for research purposes; ii) an online advertisement posted on the SCIO website; and, iii) referral by healthcare professionals in the outpatient rehabilitation clinic setting. Individuals with SCI were eligible to participate if they: 1) were at least 18 years of age; 2) had a spinal cord injury of either traumatic (e.g., fall, sporting accident, motor vehicle accident) or non-traumatic (e.g., cancer, inflammation, disc degeneration of spine, arthritis) etiology; 3) were 3-24 months post-discharge or over 10 years post-discharge from inpatient rehabilitation; and 4) were fluent in English. Caregivers were recruited through the individuals with SCI and were identified as his/her primary caregiver. Family caregivers were eligible if they: 1) were a spouse or parent of an individual with SCI; 2) described themselves as providing physical (e.g., instrumental) and/or psychological (e.g., emotional) support to the individual with SCI; 3) had regular contact with the individual with SCI (i.e., face-to-face at least weekly); and 4) were fluent in English. Recruitment began in August 2016 and
ceased in April 2017 at the point of data saturation, where successive interviews became repetitive and no new responses or themes emerged (Creswell et al., 2003).

4.2.3 Data Collection

Semi-structured interviews were conducted in-person or via telephone by the primary author. The interview questions were developed using grey and published literature, and in accordance with a recommended TheoreticalDomains Framework (TDF) interview guide (Michie et al., 2005). The TDF is an integrative framework that comprises of 14 domains and 84 constructs that could be used to inform the design of appropriately targeted interventions or evidence-based programs. Examining the facilitators and barriers to providing care to individuals with SCI using the TDF can help identify modifiable factors that can be used to develop theoretically informed interventions to support families in undertaking and sustaining the caregiving role.

The interview guides for both the care recipients and caregivers consisted of semi-structured open-ended questions. The interview guide was pilot tested with one of the authors experienced in qualitative methods as well as an individual with SCI and his caregiver. Participants were asked about the factors that facilitated and/or hindered the caregivers in undertaking and maintaining the caregiving role. Please see Table 4.1 for examples of open-ended questions from the caregiver and care recipient interviews. Furthermore, specific information was elicited on factors that have helped/hindered during rehabilitation, transition to community, and post-discharge. Probes were used during the interviews to explore emerging issues/topics in greater depth (Patton, 1990) and to allow the participants to share any
experiences they felt were necessary. All telephone and in-person interviews were audiotaped and transcribed verbatim. Informed consent was obtained at the time of the interview.

4.2.4 Data Analysis

The interviews were analyzed using inductive thematic analysis as described by Braun and Clarke (2006). Data collection and analysis were carried out in an iterative manner. The accuracy of the transcripts was verified by the first author. In order to organize and analyze the qualitative data, NVivo 10 (Castleberry, 2012) software was used. Given the potential variability in the level of support provided to an individual with SCI by different family members, the analysis was stratified based on caregiver relationship (i.e., spouses and parents). Furthermore, taking into account the learning curve that occurs within the first two years, as well as the evolving needs required by individuals with SCI over time, the differences in caregiver experiences from 3 months to up to 2 years post-discharge and over 10 years post-discharge from inpatient rehabilitation were also examined.

Beginning with open coding, a subset of the transcripts were initially coded by the primary author, and excerpts of the transcripts that described facilitators and barriers to caregiving were highlighted and written in the margin of the transcripts. Key words or phrases were combined so as to strengthen data groupings and create labels. Following this, overlapping and contrasting data between the caregivers and care recipients were identified and grouped. This provided a global perspective that is more than the sum of the individual perspectives. Furthermore, two other researchers independently coded this same subset and discussed to ensure a similar understanding of the meaning of the codes. This allowed for enhanced reflexivity and ensured rigor. New codes were integrated into the codebook as the analysis
progressed, and the codes were applied by the primary author to the remaining transcripts. Subsequently, the codes were clustered into categories and prominent themes were identified. To enhance credibility and trustworthiness, four members of the research team met over several meetings for peer debriefing sessions to discuss the analysis and interpretation of data. From this process, various thematic maps were explored until consensus was reached and theme labels were agreed upon.

4.3 Results

4.3.1 Description of Participants

The study included 34 participants, comprising of 19 individuals with SCI and 15 family caregivers. From the 34 participants, 26 individuals were in dyads (13 caregiver-recipient dyads in total), and 8 individuals participated on their own (2 caregivers, 6 care recipients). Characteristics of the caregivers and care recipients are reported in Table 4.2. The participants were recruited from Ontario (n=26), New Brunswick (n=4), Quebec (n=2), Saskatchewan (n=1), and Alberta (n=1). The majority of individuals with SCI (or individuals with SCI whose caregivers had solely participated in the study) had traumatic SCI (n=31), and the remaining (n=3) had non-traumatic SCI. Furthermore, the majority of caregivers (75%) had been providing care for over 10 years, and the remaining 25% had only been in the role for 6 months to 2 years. All participants reported that they or their caregiver had regular contact (26 lived together, and 8 saw each other at least weekly). One care recipient reported she had frequent contact with her caregiver until their recent divorce. Interviews were 45 minutes to 2 hours in length. To ensure anonymity, quotations representing the various themes only include the participants’ group (i.e., caregiver or care recipient).
4.3.2 Facilitators and Barriers to Supporting Individuals with SCI in the Community

Participants described several factors that have helped family members in the caregiving role including access to community support services, positive coping in the relationship, social support, and mastery of caregiving roles. Conversely, participants also described the factors that have hindered the caregiving role including lack of access to community resources, lack of knowledge about resources and formal training, fragmented continuity of care, negative coping in the relationship, role strain, and caregiver injury or illness. The results are presented according to the themes that emerged, with representative quotations that highlight the key elements within a theme. The characteristics of these themes associated with the facilitators and barriers are summarized in Table 4.3. Although data were analyzed based on the caregiver relationship, no major differences were found between the spouses and parents groups. However, slight variations in the barriers faced by caregivers of individuals who were injured in the last 24 months versus individuals who were injured for over 10 years were noted.

4.3.2.1 Facilitators to Providing Care

Access to Community Support Services

Many participants emphasized the importance of having access to available resources to help the family caregiver. Almost all participants reported receiving practical support by a hired personal support worker (PSW) or attendant. The services they provided included, but were not limited to, support with basic ADLs such as bathing, dressing, bowel and bladder care (e.g., catheterization), as well as support with instrumental ADLs (iADLs) such as meal preparation, and housekeeping. The caregivers mentioned that having assistance in providing care to their relative reduced their workload, and allowed them to maintain their own independence, without
having to worry about their loved ones alone at home. One caregiver emphasized the importance of having attendant services to provide assistance to her injured husband while she was away at work: “I was working, and [wondered] how he was going to be supported in the house. But thankfully, we had home care that we set up, and that took a lot of pressure off that way” (CG 9, wife). Several care recipients, who were spouses, further added that having PSWs reduced their family members’ caregiving responsibilities, which not only allowed them to have more time to focus on their relationships but also maintain their relational identities to each other (i.e., husband/wife identity):

“We were both resistant in having strangers coming into our home when it first happened. So he [CG] was helping, and it was not a good thing. Looking back, I would have put it in right away. So as soon as they [PSWs] came in and they started, it helped alleviate all the caregiving responsibilities that he felt he had. So it was much better for our relationship.” (CR 1, wife)

Some participants identified additional services that supported the caregiving role. This included professional services, such as nursing services (home visits), and day/transportation services, such as social/recreational services and transportation services (e.g., Wheel Trans). A female care recipient described how transportation services promoted independence for both her husband and herself:

“I’ll take Wheel Trans and go to the appointment. I’ll see a specialist for whatever reason I have. I try to not involve him as much you know. It’s been a hard journey, but I just wanted him to play more the husband role versus the caregiver role.” (CR 1, wife)
Positive Coping in Relationship

Several participants recognized the importance of positive coping in their relationships. Positive coping was described as how caregivers and care recipients, both individually (e.g., positive outlook) and as a dyad (e.g., open communication, reciprocity), negotiate the changes within their caregiving relationships so as to minimize the impact of SCI on the dyad. Although certain individuals with SCI, particularly those with tetraplegia, may be unable to contribute to their premorbid daily household tasks, several caregivers mentioned that the care recipient’s positive attitude/behaviour, such as being less demanding or being more appreciative, allows them to sustain their caregiving roles for a longer period. Caregivers also described that their own positive outlook or attitude toward caregiving situations allows them to cope with the caregiving role. One caregiver put it this way:

“Well, like I say, it made things a lot easier for me. I know that, after he was finished the radiation and then I was home with him for the summer, I was pretty much housebound too. I keep thinking to myself if he had been really down and depressed, I know that I would not have been able to handle it very well. Because it’s hard enough on its own to be dealing with it, but if he had been really depressed, it would not have been good at all. I am just very, very thankful that he’s had a positive outlook and his attitude is whatever. It seems like whatever is going to come of this, I’ll deal with it.” (CG 19, mother)

Aside from having a positive attitude, mutuality and reciprocity were vital to the relationship in that it encouraged an affective relationship between the caregiver and care recipient involving closeness/intimacy, interdependence, and instrumental/interpersonal exchanges. Examples of mutuality and reciprocity described by the participants include
communicating empathy, mutual understanding and respect for each other’s needs and space, and particularly interdependence (e.g., shared activities). A male care recipient stated:

“I do a little bit of laundry, like I put the stuff in the washer and transfer it to the dryer, but she folds the clothes because I really hate folding clothes. If she has a faucet leak, then I’ll fix that, so there’s stuff like that. So, we trade back and forth that way” (CR 9, husband).

Sharing household chores not only nurtured a healthy attitude toward one another, but this added help around the house reduced work overload for the caregivers.

**Social Support**

Both participant groups described the need for a supportive social environment in helping the caregivers undertake and sustain their caregiving role, especially during the early stage of returning home after discharge from rehabilitation when adjustment challenges occur. Although the majority of caregivers mentioned that they are the primary source of support, they do occasionally receive help from other family members or friends, and this typically includes instrumental support (e.g., housekeeping, or babysitting if the caregiver is a young parent) or emotional support (e.g., providing comfort). One care recipient described the support provided to her mother (primary caregiver) from other family members:

“She’ll [aunt] drop everything and come over and stay with me if mom has to go anywhere, or if she wants to go away for a weekend, anything like that, and she knows how to do the catheters, and bowel care, and all that, so mom is able to go.” (CR 5, daughter).
This added support provided a much-needed break to help the caregivers cope with the caregiving requirements and continue in the role.

Peer support was also reported as an important facilitator in caring for an individual with SCI, again, particularly early after the injury. Some participants mentioned they or their caregivers were part of a peer support group, while the individuals with SCI were in the inpatient rehabilitation centres. During the peer support group interactions, it was noted that the caregivers were able to share concerns/fears of taking on their new caregiving roles. Several participants who have been providing care for a longer period also emphasized the need for matching a caregiver stepping into the caregiving role with an experienced caregiver to share lessons learned and offer assurances:

“Sometimes we need a peer mentor. And if you hear a different way of doing something, maybe we could try that... You talk about things that you don’t talk about in public. And then just in conversation you can learn something new. It can give you an idea or you realize that someone else goes through the same thing. This is how they deal with it. Or you can give advice.” (CG 2, wife)

Although peer support groups have been identified as a key factor in helping the caregiver undertake and sustain the caregiving role, several participants, particularly in the rural regions, have mentioned they do not have access to such groups within their communities.

**Mastery of Caregiving Roles**

Having the appropriate knowledge and becoming proficient in caregiving roles, as well as having a positive view of his/her ability to master these new roles, was viewed as a facilitator.
Learning to use problem-solving skills to meet caregiving demands and feeling in control of care situations contributed to caregiver confidence and competence in the role. A spouse caregiver talked proudly and confidently about learning many of the caregiving tasks on her own and her determination to continue to learn and master new roles:

“I’ve learned everything, and any changes that come up, I’ll learn them. I will be the one that’s with him at the doctor when she says or he says, you need to do this or you need to do that. I’m going to be the one that gets that news, so I’m going to learn how to do it. They'll explain it and then we’ll go home and try it.” (CG 2, wife)

4.3.2.2 Barriers to Providing Care

Lack of Access to Community Resources

Both caregivers and care recipients echoed the same concern about the difficulty of accessing resources in the community. Many caregivers described not having access to necessary funds to provide assistance to their injured relative, such as limited funding for home modifications (during the early post-discharge stage), third party caregivers, and assistive technology. One parent caregiver discussed her frustration towards not having access to funds for third party caregivers: “You can’t afford to pay anybody, unless you are filthy rich, or you got big insurance. Nobody can afford to pay. I don’t even know what the going rate is to pay for someone, for a caretaker. I have no clue” (CG 5, mother). Family members are often required to perform roles (e.g., assistance with basic and instrumental ADLs) that would be expected of paid professionals due to limited funding/private insurance.
As much as assistive devices were reported necessary in the day-to-day routine for managing the care of the individual with SCI, several participants described the lack of access to relevant and modern assistive devices (e.g., power wheel chairs, advanced Hoyer lifts, advanced summer/winter wheelchair tires) for the care recipient as a notable barrier to undertaking and continuing the caregiving role. One care recipient talked about not having access to assistive devices that are efficient and appropriate to the user and the physical burden it causes for her mother:

“The lifts are just like the one I have, like, they're big, so you don’t want to have to move one of those in and out of the van. It’s a hassle to go anywhere...Her back gets worse and worse, and it’s not from not having the skills, it’s from not having the proper technology” (CR 5, daughter).

**Lack of Knowledge about Resources and Formal Training**

The most prominent barrier experienced by the majority of caregivers related to their difficulty in navigating the healthcare and social services system, specifically soon after the injury, in order to gain appropriate knowledge and training. Several caregivers described the challenges they encountered in providing care to the individual with SCI because they did not have knowledge of available resources in the community and how to access them (e.g., home care, assistive devices, funding programs). In fact, a number of participants mentioned the plethora of information on the Internet can be “overwhelming” and sometimes unreliable. Caregivers spent valuable time searching for information, while they were feeling unprepared for undertaking the caregiving role. A caregiver indicated her frustration in not knowing where and how to access the necessary resources soon after her son was injured:
“Because there is so much information out there, I would say that is one of the real stumbling blocks that I am finding, that between the accident, the visiting, maintaining your home life and your work, and just trying to keep up with looking after [care recipient’s] finances and his books and reporting to the Ontario Disability Support Program, there are so many things to think about. You just don’t know where to turn. Where do you go to find a personal support worker? Do you need to go through an agency or is it provided by the hospital or is that something the family is responsible for? There are so many questions and there are so many different websites to go on to. It’s almost…even that is overwhelming. So, it’s just difficult to navigate all of the information. It’s likely there, it’s just that we don’t know where to access, and how to access all of that.” (CG 15, mother)

The caregivers also reported that there was limited formal training provided to them by healthcare providers while the individual with SCI was in the inpatient rehabilitation centre. Participants considered this a notable barrier in preparing them for the caregiving role prior to their injured family member coming home. Indeed, several participants mentioned the caregivers had to learn how to provide certain basic activities through trial and error. One son stated:

“I remember one of the problems we had in the very beginning, nobody taught my parents how to do a transfer properly. That was big. Because of the surgeries I had on my spine, every time I was moved it was extremely painful. Through trial and error, my father and I actually figured out a way to do it” (CR 14, son).

Few participants went on to say that although some personal care tasks, such as catheterization, were demonstrated to the caregivers, they were not given the opportunity to
practice these daily tasks in front of the professionals, prior to going back home. As one care recipient recommended:

“Where you have training with your caregiver, your nurse, and you. That’s where you’re going to learn cathing, for example. You do it two or three times, not just once. Then you let the caregiver do it, with the nurse there. When we had it done, the nurse just showed my dad how to use the catheter, and that was it. Then, when we got home, it was like, okay, well, let’s give this a try. There are little tricks and stuff. Like, you have to watch for infections and things like that.” (CR 14, son)

In fact, several participants echoed similar recommendations. Furthermore, aside from the basic self-care tasks (e.g., bowel and bladder, transferring, etc.), several caregivers also spoke about the caregiving challenges they encountered because they were not taught how to check for signs and symptoms associated with secondary health conditions of SCI, as well as management of these symptoms (e.g., pressure injuries, autonomic dysreflexia):

“So that’s what was happening to him [autonomic dysreflexia] because I couldn’t get this catheter in. This was about, I don’t know, maybe a month after he got home. So I called an ambulance, he went and they put an indwelling catheter in at the hospital. I phoned down and there was a couple of nurses I knew and they said, well ...they knew what I was talking about that it wouldn’t go in. It’s a pity I didn’t know before I came home because I could have avoided a lot of stress for myself and [care recipient].” (CG 8, mother)

Although some participants acknowledged some basic self-care training was provided to the caregivers during inpatient rehabilitation, several participants also added they would have
wanted “emotion coaching” as well. “Emotion coaching” was described as learning how to approach the individual with SCI, being aware of the care recipient’s emotions, coping strategies for the caregivers, as well as dyadic coping strategies. One recently injured female care recipient spoke about the need for her husband to have knowledge about the emotional aspect of the injury and the caregiving process:

“Because I did so much at home, and now he’s having to not only work and stuff, but let’s just face it, they aren’t used to doing that, and it can be very frustrating. I think it would help them also, just being able to talk to somebody, and get some skills on how to deal with that frustration.” (CR 18, wife)

**Fragmented Continuity of Care**

Both caregivers and care recipients experienced dissatisfaction with the continuity of care (e.g., coordination of care, interpersonal care) provided by the healthcare providers. Several caregivers commented on the importance of discharge planning (e.g., transition between different hospital settings or into a community setting) in order to bridge the gap between different care settings and ensure continuity of care. Its perceived absence created uncertainty and made caregivers feel unprepared to take their injured family member home. One mother expressed her frustration due to the inconsistency of care between hospital settings:

“We [live in] a fairly remote area, in a small area. If there was a real crisis, you’re going to be sent to a major centre. You are there for a period of time. But then, when you are sent elsewhere [another centre], where do you go from there? For [care recipient] in the hospital, all the care was provided for when he was there. And then, you are sent to the next step, which now is in [a smaller centre]. You are dealing with all new people,
new doctors, and there, again, you are almost going backwards because you are having to start all over again. Well, where do we start now? It’s not really a continuum of the care from [a major centre], from the four months there. It’s just really hard to be patient when you are ready to keep moving forward.” (CG 15, mother)

Some caregivers were also frustrated by the lack of coordination of care during the discharge phase: “I would want to know, maybe, the steps that are involved in the care...An outline of, how are things going to look, what you can expect, and all of those things...” (CG 15, mother). Although continuity of care was considered crucial to ensure a smooth transition into the community, some participants also recognized the need for adequate follow-up (e.g., ongoing comprehensive screening, needs/resources assessment) by providers after discharge. One caregiver expressed the need for follow-up care that is responsive to the changing needs of her injured family member: “I mean, [hospital X], that is our centre, they never call us. They never get an update to see how she is doing, or if something new has come up” (CG 5, mother).

Uninformed healthcare providers, particularly, primary care providers, was recognized as a barrier to obtaining the required care. Both participant groups stated that their primary care physician had limited knowledge of the clinical issues related to SCI (e.g., symptom management) and available supportive care services. This consequently led the caregivers to seek information elsewhere such as the Internet. One care recipient described her mother’s and her experience with the healthcare providers: “The [primary] healthcare providers, if you tell them what the problem is, they’re just like, well, you’ve got to deal with it. They don’t give you options on where to call, what to do, anything” (CR 5, daughter).
In addition, although having PSWs to assist the caregivers facilitated care, the added task of training them on how to provide appropriate care was seen as a barrier. Some caregivers explained that training, and in some cases supervising, the PSWs took time away from their day-to-day activities. Moreover, some participants reported that due to recurrent turnover of PSWs, there was additional burden of retraining. A caregiver stated:

“I found that as we started getting PSWs in and support for [care recipient], I’m still the person that trains them. They sometimes come in not knowing what to do...because there are certain things that certain agencies don’t allow their PSWs to do, so I fill in those gaps.” (CG 2, wife)

The majority of participants also echoed their frustration with the limited interpersonal relations and communication among their healthcare providers. One caregiver described his disappointment in the providers’ inability to communicate empathetically with himself and his wife about the prognosis of their injured son:

“When he [CR] went to [hospital X], and the initial inspection doctor who was looking at his spine called us and said, ‘I’m sorry to say, but there is no mobility in his body below shoulders, and there is not much we can do about it.’ My wife bluntly said, ‘so what will he do with his life.’ [The doctor said] ‘oh, he can watch television.’ My wife said, ‘it means he will be a vegetable’, and the doctor didn’t know what to say, but he said, yes.” (CG 11, father)
Negative Coping in Relationship

Interestingly, both participant groups often described coping along a continuum such that there was both positive (facilitator) as well as negative (barrier) coping, within the relationship at some point during the caregiving period. A female caregiver described her experience with coping in their caregiving relationship:

“Some days are better than others. It’s a difficult process because he gets very upset. Even though we both know what it involves before we start [bowel care/routine], he gets very upset, and sometimes we fight a lot about it. But then when it’s over, it’s always a kiss goodbye and you’re fine, right?” (CG 2, wife)

Caregivers stated that although they understand their injured relative’s situation, the care recipient’s negative attitude and or disruptive behavior makes sustaining the caregiving role challenging. In fact, several care recipients also acknowledged their unwillingness to cooperate in caregiving situations, and they observed an impact on the caregivers’ mood, and ability to provide care. A male care recipient explained providing bowel care was a tough caregiving task for his wife due to his negative attitude:

“She said, ‘you’re just so angry’, and I start moving or jumping around, and she doesn’t like that, or I start yelling at her negatively, if I react and I’m not having a good day. She’s like, ‘oh, not doing it [caregiving] no more’.” (CR 2, husband)

Both caregivers and care recipients mentioned negative dyadic coping was also a key barrier to providing care. Negative dyadic coping was described as interacting in care situations in a disapproving, hostile or patronizing manner. Dependency was seen as a crucial factor
contributing to negative dyadic coping, where either (1) the care recipient was relying too heavily on the caregiver to meet nearly all of his/her needs; and/or (2) the caregiver providing assistance to the care recipient on tasks that the care recipient could do for him/herself. This resulted in work overload and burnout for most of the caregivers. A female caregiver described her husband’s dependent behaviour that resulted in her inability to provide care:

“He wants to occupy [exploit] me. He wants to occupy me, and what he can do himself, he wants me to do it, yeah. But after, in 2006, I [became] exhausted. I told him that I will not be with him, and then I went back [to parents’] home.” (CG 10, wife)

Role Strain

The majority of the caregivers experienced difficulty in meeting the demands of all their caregiving tasks due to role strain (i.e., either role overload or role conflict). For example, if the care recipient had tetraplegia or was in the early stage of injury, there was a high demand for personal care, which often resulted in role strain. Many caregivers stated that they experienced role overload where they had multiple diverse tasks including caregiving tasks, and social, work and family related duties. One mother of a tetraplegic son who was injured two years prior explained the role overload she had faced:

“It was overwhelming, believe me, for like those six months...People say how do you do it, but I think you just do it, this is what I do. Other than the fact that I work double shifts, like when you’re in a setting like that and people come and go every eight hours, they work a shift, they go home. Other than that, there are some days I wish I had more help because I have to really organize my time.” (CG 8, mother)
This role overload due to lack of resources, including time and energy, contributed to the inability of the caregivers to perform their caregiving tasks, and further accelerated the onset of caregiver burnout.

In addition, several spousal caregivers, particularly young parents, also experienced role conflict whereby they had difficulty in fulfilling the caregiving role due to incongruity between the expectations of the caregiver role and other social/relational roles (e.g., parent, employee). In addition, the unpredictable nature of events related to the onset of secondary health conditions further contributed to role conflict. A female caregiver described her feelings of burnout often due to taking on multiple roles as a caregiver for her injured husband and a mother to her children:

“House chores and driving, dealing with kids, everything I am doing myself. I had so much stress work also here [caregiving responsibilities at home]. Also, I have two kids. Now [daughter’s] five years old, and in the last five years it has been very hard to [raise] these kids. Within the last year [care recipient] has a big problem with his bowel routine so he had to go four or five times to the washroom. Sometimes he calls me, and says ‘oh, my BP is shooting so come’, while I’m driving [son to school]. So, I came [back home], but it makes me so stressed. I was so stressed.” (CG 10, wife)

**Caregiver Injury or Illness**

Caregiver health was described to have a reciprocal effect on caregiving. Participants mentioned the negative health effects resulting from providing care to individuals with SCI (e.g., occupational injury; caregiver injury/illness during the care process). This poor physical and mental health in turn was seen as a considerable barrier to being able to sustain the caregiving
role. Fatigue and physical pain (e.g., shoulder/back pain) were reported as common physical health effects of caregiving. Several caregivers stated that physical strain due to transferring was the most prominent negative effect they experienced; this was true for most caregivers of individuals with tetraplegia. One caregiver described how providing physical assistance to her tetraplegic husband, particularly lifting and transferring, had a negative impact on both her physical and emotional wellbeing:

“Actually, now I have some extra pain. I started some extra pains in my shoulders. At one time my shoulder was frozen full-time, and I couldn’t lift my shoulder. At that time, [care recipient] was saying help me to grab my hips on the bed. I told him I can’t do it. I have to do it, but I couldn’t so this made me aggressive, but aggression doesn’t count. It doesn’t help it, and also I gained so much weight. I also became depressive, and I am getting depression medicine.” (CG 3, wife)

Several care recipients further added that they were concerned about their caregivers’ ability to provide physical assistance due to aging. A son described how at the onset of his injury, his parents were already older, and this resulted in them providing limited physical assistance:

“Well, they were older so it’s not like they were young kids. When I got injured, I was 30. My parents worked, and they weren’t young so stuff that hindered was they were busy during the day so how can they help? So, we had to hire a private attendant to help me out. It worked out to be the best way. Their age and working hindered them helping me. They weren’t young, and I didn’t want them to help me… I just thought I don’t want my
mom or dad helping me because they’re older. Let somebody else do it so they don’t get stressed out.” (CR 11, son)

Another son talked about his future plan of living in a facility due to his caregiver’s deteriorating physical health as she ages:

“I’m not going to require my mom to help me when she is past the age of 65, I’m not going to expect her at the age of 80 to come and help me, no way. I’m just going to live in a facility, if need be it would have to be my last, last resort.” (CR 4, son)

Several caregivers also described the ongoing anxiety or depression due to caregiving, either due to the physical strain of providing assistance, or seeing their relative in a state that is unbearable to them. One female caregiver explained how seeing her husband in pain, has a negative reciprocal effect on her emotional wellbeing, as well as her ability to perform caregiving tasks: “Yeah, I feel very low. Actually, when he has some problem, physical problem, which he can’t handle, I also become so depressed, I don’t want to wake-up from the bed” (CG 10, wife). A few caregivers, particularly those who have been providing care for a long period, even mentioned their negative lifestyle changes, such as turning to recreational drugs or smoking, as a way to cope with the negative effects of caregiving.

4.4 Discussion

The current study aimed to identify facilitators and barriers to undertaking and sustaining the caregiving role from the perspectives of individuals with SCI and their family members. A number of factors helped family members in the caregiving role including, but not limited to: access to community support services, positive coping in the relationship, social support, and
mastery of caregiving roles. Conversely, factors that have hindered the caregiving role include: lack of access to community resources, lack of knowledge about resources and formal training, fragmented continuity of care, negative coping in the relationship, role strain, and caregiver injury or illness. A noted strength of this qualitative study is the emphasis on the lived experiences of both caregivers and care recipients and their interplay in understanding family caregiving in SCI. In addition, the majority of studies have focused on caregiver burden associated with providing care to an individual with SCI; however, this is the first study to have a primary focus on the barriers and facilitators experienced daily by caregivers. The findings from our study provide insight into factors promoting sustainable family involvement in the care process, as well as reduce negative outcomes associated with caregiving. Figure 4.1 presents a summary of the identified facilitators and barriers, as well as corresponding strategies that, if implemented within the healthcare system, could sustain family caregivers in the caregiving role long term. These are discussed below in the context of the existing literature.

The current study corroborated Chan’s (2000) finding that caregivers faced considerable caregiving challenges due to the care recipients’ negative mood and pessimism, whereby caregivers were willing to accept the injury but not the negative attitudes or behaviours. Chan (2000) suggested that communication and negotiation between the caregivers and care recipients is vital to their adjustment to changes in their lives, as well as to reach an understanding of each other’s expectations. Our results go beyond this to provide evidence that emotional awareness is also vital during caregiving situations in order to reduce maladaptation and promote helping behaviours among caregivers. Emotional awareness constitutes the capability of caregivers to recognize the care recipients’ emotional state and associated needs, use emotional information to guide problem-solving and decision-making, and manage their own emotions (Ricciardi et al.,
to adapt to caregiving situations and sustain caregiving. Being able to recognize and understand the care recipient’s emotional states motivates helping behaviours (Ehmann, 1971), reduces emotional burden, and increases satisfaction with caregiving activities (Lee & Brennan, 1999). Furthermore, it has potential to minimize negative reciprocal effects of mood and behaviour during caregiving situations, as well as to increase motivation and willingness to accept and sustain the caregiver role. Emotional awareness in caregiving is not a well described topic in current literature; nonetheless, this is an important area that must be further explored in order to promote sustainable family involvement in community caregiving. Considering that the care recipient’s personality and behaviour play a major role in the caregiving process, the participants in the current study suggested “emotion coaching”, particularly offered during inpatient rehabilitation. Emotion coaching implies training family members to build the appropriate interpersonal skills to successfully tackle caregiving tasks that require high intensity emotional coping. For example, training caregivers to perform certain complex caregiving tasks (e.g., bowel care routine, autonomic dysreflexia management) while simultaneously addressing the psychoemotional needs of the care recipients (i.e., understanding and validating recipients’ feelings and concerns) through the use of empathy is recommended.

A number of studies have documented that perceived social support has been linked to lower caregiving burden (Chan, 2000), reduced sense of social isolation (Sheija & Manigandan, 2005), and better psychological adjustments in family caregivers of individuals with SCI (Chandler et al., 2007). As such, the present findings extend those of previous authors in that participants in the current study identified social support as reducing caregiver burnout and enhancing positive adaptation to the injury. Particularly, our findings build upon previous studies (Sheija & Manigandan, 2005; Boschen, Tonack & Gargaro, 2005; Conti et al., 2016) by
delineating the role of peer mentors within the supportive social network in preparing caregivers, for their caregiving role. The need for support from caregiving peers became of greater importance prior to discharge from inpatient rehabilitation when caregivers required practical advice about supporting individuals with SCI in the community. However, our findings further suggest that accessibility to peer support groups is varied based on geography, such that caregivers living within rural areas had difficulty connecting with a peer mentor. Efforts should be increased to build virtual peer support networks for caregivers, to improve their preparedness, accommodate their emotional/mental health needs (Boschen, Tonack & Gargaro, 2005) and reduce social isolation (Sheija & Manigandan, 2005) in both rural and urban settings.

Furthermore, our findings suggest that additional social support, in the form of instrumental support (e.g., housekeeping), can provide greater flexibility to maintain a work-life balance, and allow the caregivers to provide assistance to their relatives with SCI, while retaining their personal and social identity. This was also noted in another qualitative study that explored the impact of caregiving on employment with primary caregivers of individuals with SCI (Ellenbogen et al., 2006). Participants described the challenges associated with balancing caregiving and work responsibilities, as well as the importance of having external support in providing caregivers greater flexibility to continue to balance their many roles (Ellenbogen et al., 2006). While additional support was perceived as helpful in reducing role strain, several participants in our study noted the added stress and dissatisfaction with paid caregivers, indicating a lack of training, high turnover, substandard quality of care, and recurrent inconvenience caused due to the need to provide constant supervision. In other words, the burden of training and supervising paid caregivers outweighed the benefits (e.g., reducing role strain). As a result, individuals with SCI and their family caregivers often feel reluctant to hire third
party help, even when the caregivers are feeling burned out (Charlifue et al., 2016). Future research should be directed towards identifying core areas of practice for hired caregivers (i.e., PSWs specializing in SCI care) in order to develop the PSW role to its full potential and enhance formal care delivery within the home care system.

A recent study by LaVela and colleagues (2015) reported that a greater proportion of caregivers of individuals with SCI experienced insufficient sleep and more days without sleep in comparison to caregivers of those with other neurological conditions. These negative physical outcomes are possibly associated with reasons unique to SCI caregivers, such as being required to reposition the care recipient during the night in order to prevent pressure injuries (LaVela et al., 2015) or daily bowel evacuation and 4-6 times daily bladder emptying (Nogueira et al., 2012). Our participants reported fatigue and physical pain (due to transferring), as recurrent adverse health effects attributable to caregiving, which inhibited their ability to provide appropriate care. The similarities between our findings and other studies, indicates that interventions to improve the health and well-being of family caregivers could incorporate increased night time or respite care for temporary relief from the caregiving responsibilities (LaVela et al., 2015). Research is needed to understand the impact of interventions that include respite care and/or evening care on the incidence and prevalence of caregiver injury, as well as the frequency and severity of caregiver burden.

The participants in the current study reported that the caregivers receive very little guidance from healthcare professionals in managing the physical and emotional demands of caregiving. Among the greatest challenges for family caregivers is navigating the healthcare system and transitioning back home. Discharge from inpatient rehabilitation is a crucial moment in the care trajectory for caregivers, and our findings are consistent with previous studies.
describing the discharge phase as characterized by elevated anxiety, and concerns due to clinical, logistical and organizational issues (Marini & Reale., 2010; Lucke et al., 2004; Schulz et al., 2009). Caregivers’ limited involvement in the injured individual’s care during rehabilitation might contribute to family members experiencing anxiety in undertaking the caregiving role post-discharge. Caregivers in the current study reported that they did not receive substantial information or training prior to discharge. The majority reported they had to learn certain caregiving tasks through trial and error at home in the community. Greater effort is needed to provide family members with enhanced access to community resources, education, and particularly skills training (prior to discharge from inpatient rehabilitation) that go beyond the basic physical aspects of care, such as problem-solving skills (e.g., emotion coaching), in order to prepare them to undertake the caregiving role. In fact, the caregivers in our study described the challenges and consequences of not having the appropriate skills to assess and interpret symptoms associated with secondary conditions of SCI, such as tissue injury and autonomic dysreflexia. Indeed, a study by Elliott and Berry (2009) corroborated our findings, as they found that poor problem-solving abilities among caregivers correlated with the occurrence of pressure injuries and adjustment issues of the individuals with SCI during the early phase of the injury.

When caregiving challenges occur, they often have a negative impact on the family caregiver and care recipient alike, which can lead to substandard symptom management, emergency hospitalizations, and unscheduled physician visits (Guilcher et al., 2013). Thus, intervention programs should be designed to include coaching of caregivers to develop problem-solving skills and achieve mastery in situations where they are facing difficulties in caregiving, rather than the more commonly provided general information in written format. Healthcare professionals need to conduct routine assessment of caregivers’ needs, which are continuously
evolving depending on the timing and setting across the care trajectory (Cameron & Gignac, 2008). Furthermore, in relating our data with existing literature, we can affirm that additional professional support from nurses, such as making home visits (i.e., follow-up care), could facilitate not only providing continuity after discharge from inpatient rehabilitation, but could also contribute to positive adjustment and adaptation between the caregiver and care recipient (Boschen, Tonack, & Gargaro, 2005; Hammell, 2004).

4.4.1 Limitations

Despite the strengths of the current study, a few possible limitations apply. Study limitations are related to bias in the recruitment of participants. It is possible that those who decided to participate may have been better adjusted to the caregiving role than those individuals who declined participation. This is perhaps a likely reason for an over-representation in the over 10 years post-discharge group as they have had more time to adjust to living with SCI or providing care. Also, a majority of participants in the current study are from urban areas. There might have been a geographic variation in the factors that have facilitated and hindered the caregiving role, such as environmental barriers or resource scarcity, not captured in our study. Future research should be directed towards determining if the experiences and concerns of family caregivers living in rural versus urban settings differ substantially.

4.4.2 Conclusion

Overall, the current study demonstrated that positive coping, social support, skills training, access to community services, and continuity of care contribute substantially to the sustainability of the SCI family caregiving role. Furthermore, considering the immediate roles that caregivers assume upon rehabilitation discharge, the findings from the current study
articulate the need for better integration of family members during the rehabilitation and discharge processes, to better prepare them for the caregiving role. These findings should further alert healthcare and rehabilitation professionals to conduct routine needs assessment of caregivers at regular intervals. Despite an abundance of research studies highlighting the distress and burden associated with caregiving for a family member following a SCI, there continues to be a lack of evidence-based interventions to sustain the role of family caregiving. Therefore, the facilitators and barriers to providing care for an individual with SCI identified in this study can be used as a foundation to contribute to the design of rehabilitation interventions that focus on facilitating the caregiving role, while at the same time reducing caregiver burden.
Table 4.1: Examples of Open-Ended Questions from the Interview Guides for Facilitators and Barriers to Caregiving

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Caregiver: What are some things that have helped you in providing care to your family member?</td>
</tr>
<tr>
<td>2.</td>
<td>Caregiver: What are some things that have hindered you in providing care to your family member?</td>
</tr>
<tr>
<td>3.</td>
<td>Caregiver: What kind of training or information did you feel you needed during rehabilitation in order to</td>
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<tr>
<td></td>
<td>assist your family member (after discharge)?</td>
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<tr>
<td>4.</td>
<td>Care recipient: Was there any incident where your family member felt a certain caregiving task was</td>
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<td></td>
<td>difficult to do? Why?</td>
</tr>
<tr>
<td>5.</td>
<td>Care recipient: Do you think the community health services (if available within their community) help your</td>
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<td></td>
<td>family member in providing care to you? If so, how?</td>
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<tr>
<td>6.</td>
<td>Care recipient: What could health care providers or community health services do to help your family member</td>
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<tr>
<td></td>
<td>assist you better on a daily basis?</td>
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### Table 4.2: Characteristics of Participants in the Study

<table>
<thead>
<tr>
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<td>Female</td>
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<td><strong>Time since discharge from inpatient rehabilitation (years)</strong></td>
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<td><strong>Age (range; mean)</strong></td>
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</tr>
<tr>
<td>Unemployed/retired</td>
<td>7</td>
</tr>
<tr>
<td><strong>Relationship to individual with SCI</strong></td>
<td></td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td>8</td>
</tr>
<tr>
<td>Parent</td>
<td>7</td>
</tr>
<tr>
<td><strong>Age (range; mean)</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>41-82; 61</td>
</tr>
</tbody>
</table>
Table 4.3: Summary of Facilitators/Barriers to Providing Care, and Associated Examples

<table>
<thead>
<tr>
<th>Facilitators</th>
<th>Examples of Facilitators to Providing Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Community Support Services</td>
<td>- Professional Services (i.e. physiotherapy, nursing home visits)</td>
</tr>
<tr>
<td></td>
<td>- Attendant Services (i.e. personal support workers)</td>
</tr>
<tr>
<td></td>
<td>- Day Services (i.e. transportation services, respite care)</td>
</tr>
<tr>
<td>Positive Coping in Relationship</td>
<td>- Positive Individual Attitude/Behaviour (i.e. CR attitude- independent, appreciative; CG attitude- optimistic)</td>
</tr>
<tr>
<td></td>
<td>- Positive Dyadic Coping (i.e. interdependence- shared activities; interpersonal exchanges- communicating empathy)</td>
</tr>
<tr>
<td>Social Support</td>
<td>- Family and Friends Support (i.e. instrumental and emotional support)</td>
</tr>
<tr>
<td></td>
<td>- Peer Support (i.e. appraisal, informational and emotional support)</td>
</tr>
<tr>
<td>Mastery of Caregiving Roles</td>
<td>- Caregiver Confidence (i.e. satisfaction with own performance/feeling in control of care situations)</td>
</tr>
<tr>
<td></td>
<td>- Caregiver Competence (i.e. becoming proficient in problem-solving skills to meet care demands effectively)</td>
</tr>
<tr>
<td>Barriers</td>
<td>Examples of Barriers to Providing Care</td>
</tr>
<tr>
<td>Lack of Access to Community Resources</td>
<td>- Lack of Access to Funding (i.e. limited funding for third party caregivers, assistive technology, home modifications)</td>
</tr>
<tr>
<td></td>
<td>- Lack of Access to Assistive Devices (i.e. electric wheel chairs, advanced Hoyer lift)</td>
</tr>
<tr>
<td>Lack of Knowledge about Resources and Formal Training</td>
<td>- Lack of Knowledge on Available Community Resources (i.e. where and how to access available community resources- home care, funding programs)</td>
</tr>
<tr>
<td></td>
<td>- Limited Formal Training for Caregivers (i.e. skills training → instrumental &amp; cognitive skills)</td>
</tr>
<tr>
<td>Fragmented Continuity of Care</td>
<td>- Uninformed Primary Healthcare Providers (i.e. limited knowledge of clinical issues and available supportive care services)</td>
</tr>
<tr>
<td></td>
<td>- Inconsistent/Uncoordinated Care (i.e. lack of coordination during discharge phase, no ongoing comprehensive screening &amp; needs/resources assessment)</td>
</tr>
<tr>
<td></td>
<td>- Personal Support Worker Training (i.e. instrumental training, constant supervision)</td>
</tr>
<tr>
<td></td>
<td>- Limited Interpersonal Relations and Communication (i.e. healthcare providers not easily accessible/communicating empathy)</td>
</tr>
<tr>
<td>Negative Coping in Relationship</td>
<td>- Negative Individual Attitude/Behaviour (i.e. CR attitude- uncooperative, aggressive; CG attitude- inability to cope/reluctant)</td>
</tr>
<tr>
<td></td>
<td>- Negative Dyadic Coping (i.e. co-dependence- enabling behaviours)</td>
</tr>
</tbody>
</table>
| Role Strain                                      | - Role Overload (i.e. difficulty meeting all caregiving demands due to lack of resources, including time and energy)  
|                                                | - Role Conflict (i.e. difficulty fulfilling caregiving obligations due to incongruity between expectations of the caregiver role and other social/relational roles) |
| Caregiver Injury or Illness                    | - Poor Physical Health (i.e. physical strain due to caregiving - transfers; age-related health issues - comorbidities)  
|                                                | - Poor Mental Health (i.e. progressive anxiety or depression due to caregiving) |

CR, care recipient; CG, caregiver
<table>
<thead>
<tr>
<th>Facilitators</th>
<th>Potential Strategies for Program of Intervention</th>
<th>Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Community Support</td>
<td>- Providing emotion coaching</td>
<td>Lack of Access to Community Resources</td>
</tr>
<tr>
<td>Services</td>
<td>- Building peer support networks in urban and rural regions</td>
<td>Lack of Knowledge about Resources &amp; Formal Training</td>
</tr>
<tr>
<td>Social Support</td>
<td>- Providing respite for the caregiver</td>
<td>Fragmented Continuity of Care</td>
</tr>
<tr>
<td>Positive Coping in Relationship</td>
<td>- Conducting routine needs assessment</td>
<td>Negative Coping in Relationship</td>
</tr>
<tr>
<td>Mastery of Caregiving Roles</td>
<td>- Ensuring follow-up care post-discharge</td>
<td>Role Strain</td>
</tr>
<tr>
<td></td>
<td>- Coaching in problem solving and achieving mastery in caregiving situations facing difficulty</td>
<td>Caregiver Injury or Illness</td>
</tr>
</tbody>
</table>

Figure 4.1: Identified facilitators and barriers, and corresponding strategies for program of intervention to promote sustainable family involvement
Chapter 5

Family Caregiving: Factors Associated with the Need for More Support for Individuals with Spinal Cord Injury

Abstract

**Purpose:** Individuals with spinal cord injury (SCI) often experience physical limitations, as well as multiple challenges with their psychological and social functioning and require support throughout their lifetime. Therefore, we sought to explore the perceptions of individuals with SCI and their family caregivers regarding: 1) the different types of support needed by individuals with SCI; and, 2) the factors associated with the need for more support.

**Methods:** A qualitative descriptive approach was used with semi-structured interviews. An inductive and summative approach to qualitative content analysis was employed to identify patterns and quantify data arising from accounts of individuals with SCI (n=19) and their family members (n=15).

**Results:** The following types of support needed by individuals with SCI were identified: practical (self-care activities, instrumental ADLs, management of secondary health conditions), emotional (moral support, ensuring social interaction/integration), and advocacy. The following factors associated with the need for more support were also identified: a higher level of injury, greater frequency of secondary health conditions (e.g., neurogenic bowel dysfunctions and pressure injuries) and age of the care recipient (older individuals with SCI).

**Conclusions:** The current study demonstrated the complex care tasks that family caregivers provide and calls into question the role of the formal health care system in providing care to meet the needs of this population. Future programs need to be designed to address the support needs
identified during various time points when individuals with SCI and their family caregivers require additional support from the healthcare system.
5.1 Introduction

In Canada, there are more than 1,500 new spinal cord injuries (SCI) annually, and currently, there are approximately 86,000 people living with SCI (Farry & Baxter, 2010). These injuries often consist of motor, sensory and autonomic system deficits, and/or bladder and bowel dysfunction (DeSanto-Madeya, 2009), all of which limit the individual’s ability to independently and efficiently carry out common self-care activities and activities of daily living (ADLs) and move about their home and community. In addition to the physical limitations, most individuals with SCI also encounter multiple challenges with respect to their psychological and social functioning and require support throughout their lifetime (Kemp, 2002; Thompson, 1999).

Previous research has highlighted injury-related factors that are prevalent among those individuals who experience a decline in their function post-SCI. In a cross-sectional study by Thompson (1999) involving 150 individuals with SCI, 24 percent reported a significant decline in their ability to perform common daily tasks post-acute SCI. On average, the group experiencing this decline was older (45 years or older) and were more than 18 years post injury. Pressure injury, changes to bowel and bladder functions, urinary tract infections (UTI), weight gain, and cardiovascular disease were correlated with a decline in function, and the ADLs prominently affected were bathing, dressing, and transfers (Thompson, 1999). In a more recent cross-sectional study with an aging SCI sample, Hitzig and colleagues (2008) also found that as individuals with SCI age, they are more likely to experience secondary health conditions (e.g., high blood pressure and respiratory complications increased per year with age). These findings provide evidence highlighting the current needs of the aging SCI population and demonstrated the need for increased resources aimed at the prevention and treatment of secondary health conditions (Hitzig et al., 2008).
Similarly, using a prospective longitudinal cohort database, Charlifue and colleagues (1999) examined 315 individuals with SCI at 5, 10 and 15 years post-injury, who were subsequently reassessed 5 years later. The findings from the cross-sectional and longitudinal analysis by age categories (<30 years, 30-50 years, >50 years) suggested that there was a significant correlation between increasing need for more assistance with ADLs and increasing age. In contrast, Pentland, McColl and Rosenthal (1995) found that in their cross-sectional study of 83 spinal cord injured men, while increased age was associated with increased fatigue and decreased activity level, functional independence (as measured by the Functional Independence Measure [FIM]) was not related to increased age. The authors stated that a possible explanation for this finding is that perhaps fatigue does not interfere with daily self-care activities as measured by the FIM; however, with increasing age, fatigue does limit activities related to being active in the community (Pentland, McColl & Rosenthal, 1995). When comparing individuals with SCI to the general population, individuals with SCI require assistance approximately twice as often in comparison to aging individuals in the general population and need personal care assistance up to 7 times more often (Eisenberg & Saltz, 2010). The combined effects of multimorbidity and functional decline can overwhelm available caregiving resources as individuals with SCI age.

Whilst there is considerable literature on the nature of functional decline and the increasing physical dependence that accompanies aging with a SCI, there are gaps in our understanding. There is limited information regarding the types of support needed post-discharge (both immediately and years after discharge), as well as factors affecting the levels of support needed by individuals with SCI in order to enhance or maintain health and wellbeing. Thus, the specific objectives of this study were to determine: 1) the different types of support needed by
individuals with SCI; and 2) the factors associated with the need for more support from the perspective of individuals with SCI and their family caregivers.

5.2 Methods

5.2.1 Design

A qualitative descriptive approach was used (Sandelowski & Barroso, 2003; Sandelowski, 2010). This approach is well-accepted for exploring topics about which little is known and is particularly useful for producing policy recommendations (Sandelowski, 2000; Sandelowski, 2010). Due to the important synergistic effects of caregiving whereby caregivers and care recipients mutually affect each other (Schulz et al., 2009), this study addressed its objectives by including both the individuals with SCI and family caregivers. The data used in this study were based on qualitative interviews conducted by the primary author from a larger study exploring the support needs of family caregivers of individuals with SCI. Research ethics approval was obtained from the University Health Network and the University of Toronto. All participants provided informed consent at the time of the interview. A summary of the methodological approach used in this study is outlined below (detailed procedures have been described in Chapter 4).

5.2.2 Participants and Recruitment

Community-dwelling individuals with SCI and their family caregivers in Canada were recruited to participate from three sources: a national database, a provincial community-based organization, and an outpatient rehabilitation clinic. Individuals with SCI were eligible to participate if they were at least 18 years of age, had a SCI of either traumatic (e.g., sporting
accident, fall, motor vehicle accident) or non-traumatic (e.g., inflammation, disc degeneration of spine, cancer, arthritis) etiology, were 3-24 months post-discharge or over 10 years post-discharge from inpatient rehabilitation, and were fluent in English. Family members were recruited through the individuals with SCI. They were included if they were his/her primary caregiver, were the spouse or parent, described themselves as providing physical and/or psychological support, and had regular contact with the injured individual (i.e., face-to-face at least weekly). Participants were recruited between August 2016 and April 2017. Recruitment ceased when the study reached data saturation, whereby successive interviews became repetitive and no new responses or themes emerged (Creswell et al., 2003).

5.2.3 Data Collection and Analysis

Data collection entailed semi-structured interviews in-person or via telephone. All interviews were audiotaped, transcribed verbatim, and reviewed for accuracy. NVivo 10 (Castleberry, 2014) was used to manage and organize the data.

Using a qualitative content analysis approach, as described by Hsieh and Shannon (2005), data were analyzed in a 2-stage process. With respect to the first objective, an inductive approach to qualitative content analysis was used to determine the types of support needed. Beginning with open coding, a subset of the interview transcripts were first examined for words or phrases that summarized participants’ direct verbalizations of the types of support needed from family caregivers post-discharge (i.e., assistance needed with specific activities, such as ADLs). Overlapping and contrasting data between care recipients and caregivers were subsequently grouped. Next the codes were grouped into categories that are reflective of the various types of support (e.g., activities related to practical support). In acknowledgement of the variability in the
types of support needed based on impairment related and sociodemographic factors, a second level of analysis was performed to determine the various factors associated with the need for more support (second objective of the study). Using a summative approach to qualitative content analysis, the initial part of the analysis technique consisted of quantifying the data (i.e., determining the frequency of types of support with specific activities) within various factors associated with the need for more support. For example, determining the frequency of the different types of practical support needed with respect to the level of injury allowed for comparison between the paraplegic and tetraplegic groups. This type of analysis further allowed the authors to identify patterns in the data and to contextualize the identified codes (e.g., interpreting why the tetraplegic group required more support with a specific activity) (Morgan, 1993). Following the comparisons of content, interpretation of the underlying context was conducted. To enhance reflexivity and rigor of the study, two other researchers further independently coded the same subset of transcripts. Furthermore, to increase trustworthiness and credibility, four members of the research team had ongoing peer debriefing sessions to discuss the analysis process, interpretation of data, and consensus of the labels.

5.3 Results

5.3.1 Description of Participants

A total of 34 individuals, comprising 19 individuals with SCI and 15 family caregivers participated in the study. From the 34 participants, 26 individuals were in dyads (13 caregiver-recipient dyads), as well 6 care recipients and 2 caregivers were also interviewed. Characteristics of the care recipients and family caregivers are summarized in Table 5.1. The majority of family
caregivers had been providing support to their injured relative for more than 10 years, while the remaining 25% had only been in the caregiving role for 6 months to 2 years.

5.3.2 Types of Support Needed

Most individuals with SCI often required, and in most cases received some kind of support from their family caregivers. The types of support needed from caregivers included practical, emotional and advocacy (as described in Table 5.2). Regarding practical support, several of the care recipients reported requiring ongoing support with self-care activities, such as bathing, dressing, transferring, personal hygiene/grooming, and bowel and bladder care (e.g., catheterization, digital stimulation, suppository). Several caregivers described assistance provided with instrumental ADLs (iADLs), including preparing meals, housekeeping, transportation/driving, and managing finances. Both caregivers and care recipients reported they received help from third party paid caregivers (e.g., personal support workers [PSWs]) with certain iADLs, specifically housekeeping, laundry, meal preparation, grocery shopping, and transportation/driving). Instrumental support provided by caregivers were dependent on the amount of paid housekeeping they received. In addition, the majority of individuals with SCI emphasized the need for more support from their caregivers with injury-specific tasks, such as assessing and managing secondary health conditions. Several examples of such support included bowel dysfunction management (e.g., colostomy care), UTI management, autonomic dysreflexia (monitoring heart rate, blood pressure, body temperature), skin checks/pressure injury management, and administration of medications and nutritional intake. Family caregivers were least involved during their exercise routines (e.g., stretching exercises). Several care recipients preferred their family caregivers to attend to tasks related to their self-care and management of
secondary health conditions, rather than a third-party care provider due to the high quality and intimacy of the care task.

Emotional support was given often by the majority of family caregivers. Both participant groups indicated that family caregivers play a major role in providing moral support, such as encouragement or building confidence when the individuals with SCI are showing symptoms of depression. A few mentioned that such moral support resulted in care recipients having a sense of personal autonomy towards their health care (e.g., encouraging the individuals with SCI to perform self-care activities to maintain good health, or to think for themselves so they are accountable for their own day-to-day activities). Post-discharge, several care recipients commented on the support required to get “back into the community”. Care recipients mentioned how their family caregivers supported social interaction/integration, such as encouraging focus on their relational identity (e.g., taking on the parental role), empowering them to be productive members of society (e.g., becoming a peer mentor), and encouraging them to participate in recreational activities (e.g., adaptive sports or parasports).

Becoming an advocate is an important family caregiver role, in the care and support of an individual with SCI. Participants across both groups described the importance of having a family caregiver speak on behalf of the individual with SCI when necessary (e.g., when the individual is ill, or apprehensive to communicate their needs and concerns), particularly to healthcare professionals to obtain the appropriate health services. The care recipients stated that their family caregivers were most knowledgeable about their health care needs and concerns and were able to navigate the healthcare and social services systems in a timely manner to get access to: medical help (for optimal symptom management), community resources (for enhanced assistive devices), and counseling.
5.3.3 Factors Associated with the Need for More Support

The type of support needed from family caregivers was dependent on several impairment related and sociodemographic factors, including level of injury, frequency of secondary health conditions, and age of the care recipient. With respect to the level of injury, individuals who were paraplegic required less support with self-care tasks (e.g., catheterization) compared to individuals with tetraplegia. Several paraplegic care recipients reported they had more functional independence to follow self-care routines; however, few added they needed support from their family caregivers with transfers, and bowel and bladder care in public places due to environmental barriers. A few family caregivers reported that individuals with tetraplegia required round the clock assistance. Tetraplegic participants reported they required assistance with catheterization, particularly intermittent catheterization (IC) care due to the frequency of catheter changes. This process evidently leads to bladder infections (e.g., UTI) requiring further care from family caregivers. This injury-level group further emphasized the need for more support with interval repositioning (throughout day and night) to prevent pressure injury. In addition, emotional and advocacy support, was given often or always by the majority of family caregivers.

Secondary health conditions were associated with an increasing need for support from caregivers in the area of self-care; specifically, the management of secondary health conditions. Those needing more support experienced neurogenic bowel dysfunctions, resulting in constipation. Regarding bowel management, participants reported that care recipients required support with insertion of suppositories and enemas, performing digital stimulations and management of colostomy bags, as well as administering nutritional intake (e.g., ensuring adequate fluid and fibre). Similarly, several participants mentioned the need for support with
neurogenic bladder dysfunction management, usually detrusor overactivity or incontinence. The type of support needed by the majority of individuals with SCI experiencing bladder problems included: the common procedure of catheterization (i.e., IC); and the occasional assistance with UTI management, such as more frequent ICs or condom catheter changes, and provision of medication. Several participants reported that bowel and bladder problems sometimes resulted in episodes of autonomic dysreflexia, whereby considerable and immediate assistance from the family caregivers was required. Both participant groups mentioned blood pressure monitoring was necessary to prevent or manage autonomic dysreflexia secondary to bladder overdistension, a blocked or kinked catheter, or constipation. Finally, pressure injuries were reported as the most common secondary health conditions of SCI (along with constipation) due to immobility and spasticity, and were associated with the need for more support in prevention and management. The majority of participants emphasized the need for support from caregivers with skin management, such as frequent and interval re-positioning, checking skin integrity, cleaning and moisturizing the skin regularly, and application of dressings.

Lastly, age of the care recipient was also a contributor to the need for more support from caregivers. Participants reported older individuals with SCI (age >45), compared to younger care recipients, needed more help with the management of secondary health conditions and general self-care activities, particularly bowel/bladder care and transfers, to maintain a certain level of function. However, it should be noted that the level and completeness of injury were also mediating factors in needing more support within the older population. Support with instrumental ADLs was also more prominent within the older population. The majority of participants reported receiving help from PSWs for housekeeping, recognizing that older caregivers required additional help to care for their injured family members. With respect to
medical complications, older care recipients reported experiencing comorbidities associated with aging that required additional support from caregivers. Two common chronic conditions included dementia and diabetes. Several individuals mentioned that timely administration of medication and good nutrition to reduce both age and injury-related conditions was a crucial part of day-to-day care activities. In addition, a few care recipients described the importance of needing psychological support from their family caregivers when they showed signs of dementia (i.e., decline in memory) in order to maintain their day-to-day activities, particularly self-management of tasks (e.g., taking medications).

5.4 Discussion

The current study aimed to identify the types of support needed and the factors associated with the need for more support among individuals with SCI post-discharge from the perspectives of individuals with SCI and their family members. The types of support needed by individuals with SCI from their family caregivers included but was not limited to: practical (i.e., self-care activities, iADLs, management of secondary health conditions), emotional (i.e., moral support, ensuring social interaction/integration), and advocacy. In addition, the factors associated with the need for more support included: a higher level of injury, greater frequency of secondary health conditions including but not limited to constipation and pressure injuries, and age of the care recipient (i.e., older individuals with SCI). Given that individuals with SCI commonly rely on family members to provide daily assistance, such knowledge can help identify strategies to support caregivers in the tasks they are expected to undertake in supporting their injured relatives.
The findings from the current study confirm those of previous studies in that the majority of participants in our study often required some form of emotional, practical or logistical support from their family caregivers, with practical support (e.g., assistance with ADLs) being the most prominent and most frequent. Similar to our study, Kemp (2002) found that for most individuals, paid care was received in addition to informal care by a family member. The personal assistance needs, particularly support with self-care (e.g., bathing, dressing, transferring, etc.), described by the participants in the current study demonstrates the crucial role family members play in meeting the caregiving needs of individuals with SCI. Indeed, the findings from the current study suggest that family caregivers undertake responsibility for intricate and complex caregiving tasks, particularly medical related (e.g., managing secondary health conditions); however, questions remain as to patient preferences, the extent to which family members should provide such support, in lieu of formal caregivers (e.g., visiting nurses, PSWs, etc) and the implications for caregiver burden. Nonetheless, it is important to note that the findings from the current study corroborated Berry and colleagues’ (1995) finding that the quality of care received from informal caregivers (e.g., family members) seems to match or exceed that received from formal caregivers (e.g., PSWs). Additional research is warranted to compare the care received between informal and formal caregivers, in relation to standardized metrics for quality, caregiver skill and competency, corresponding health outcomes, and implications for cost to the health care system.

While previous studies have emphasized the physical assistance provided by family caregivers (Post, Bloemen & de Witte, 2005; Thompson, 1999; Dickson et al., 2010), the current study also highlights the significant psychological support that caregivers provide. Particularly, our findings suggest that family caregivers play a vital role in promoting community re-integration post-discharge, an important goal of rehabilitation (Forchheimer & Tate, 2004).
Indeed, rehabilitation’s goal is to promote the process of community re-integration by assisting the individuals with SCI to restore formerly existing roles and relationships, to the degree possible (Dijkers, 1998). In addition, the current study participants further described the impact of psychological support provided by caregivers to enhance/encourage health-promoting behaviours (i.e., self-management).

Personal experience taking care of an individual with SCI and knowing his/her needs and concerns, puts the family caregiver in a unique position to act as an advocate. Previous studies have emphasized the importance of having an advocate to act as a liaison between the physician/healthcare system and the patient; this has been particularly emphasized in the cancer literature (Wilcox & Bruce, 2010). However, unlike cancer care, with an established professional role (e.g., oncology nurse navigators) within the healthcare system to aid patients, the family caregiver must, in most cases, assume this role for the individual with SCI. This finding corresponds with Guilcher and colleagues’ (2013) study in recognizing that caregivers of individuals with SCI, often defined as the “secondary care team”, play a critical role in filling in the gaps that currently exist within the formal health care system.

As expected, the level of injury affected the degree of functional independence and the need for more support. Tetraplegic individuals are more dependent on their family caregivers for assistance with ADLs; whereas, those with paraplegia are able to live independently with accommodations as needed or with some personal care assistance. The participants in our study reported family caregivers of individuals with tetraplegia spent a considerable amount of time performing care tasks, both throughout the day providing assistance with ADLs, and during the night with tasks such as IC and repositioning. Our findings affirm prior reports that the higher the neurological level of injury, as in the case of individuals with tetraplegia, the greater the time
spent in care by family caregivers (Rabeh & Caliri, 2010; Blanes, 2005). Considering that individuals with tetraplegia are dependent on lifetime care, the failure in the planning of care (i.e. preparation for the caregiver role) may result in caregiver burden (Nogueira et al. 2012). For example, ongoing training for caregivers (e.g., training in the management of secondary health conditions associated with aging tetraplegic individuals) could be one avenue to reduce caregiver burden. In addition, evidence-based programs that can reduce reliance on caregivers through increased independence among individuals with SCI, along with those that enhance or sustain quality of care provided through additional community support (e.g., increased personal assistance services for complex patients) could ultimately reduce caregiver burden.

With respect to age and the need for more support, a study by Liem and colleagues (2004) reported that individuals requiring more assistance with ADLs are significantly older and had lived longer with a SCI, compared to those not requiring more assistance. The authors indicated that the need for more assistance with ADLs is suggestive of functional decline, that is a result of being older with SCI. Our findings also suggest that older individuals with SCI require more support on a daily basis, particularly, with the management of secondary health conditions, due to medical conditions associated with old age. In support of this, Dickson and colleagues (2010) showed that function in individuals with SCI does not improve over time, which may result in unique challenges brought about by the combined effects of aging and injury (Schulz et al., 2009), and thus, requiring more support from caregivers. Considering that family members are also aging and could be facing their own functional limitations (Thompson, 1999), it is imperative to recognize the additional physical assistance required by family caregivers in continuing to provide care to individuals with SCI. A greater effort may be needed to provide this cohort with enhanced access to community resources, and coverage for personal care and in-
home assistance. Furthermore, as caregivers’ support needs change as the care recipient and
caregiver age, timed and tailored interventions based on caregivers’ “readiness” to receive such
specific support might also be beneficial (Cameron & Gignac, 2008).

Participants commented that the most influential factor associated with the need for more
support was secondary health conditions associated with SCI, particularly constipation and
pressure injury. The effects of neurogenic bowel dysfunction become more apparent and
frequent with older age. Aside from the gastrointestinal (GI) tract being affected acutely in SCI,
progressive changes in health status involving additional medications (associated with GI side
effects), ongoing immobility, changes in nutrition, increasing difficulty with bowel evacuation,
and more time needed for bowel care results in a decline in independence, and the reduced
ability to perform daily activities (Liem et al., 2004). This eventually results in the need for more
support from family caregivers to perform daily tasks, previously done independently by the care
recipient. As our participants reported, previous studies have also found that ongoing assessment
of appropriate bowel management, regular medication review, and monitoring nutritional status
are constantly required for an effective bowel management regimen (Chen & Nussbaum, 2000;
Correa & Rotter, 2000; Badiali et al., 1997; Stiens, Bergman & Goetz, 1997), which caregivers
must diligently follow.

Regarding pressure injuries, a study by Liem and colleagues (2004) reported that there
may be some risk factors for pressure injuries that are related to an increased SCI severity, such
as completeness of SCI, immobility, severe spasticity, and urinary incontinence. Therefore,
pressure injuries are directly related to the need for more assistance with daily activities.
Participants in our study emphasized the need for more support from family caregivers in
preventing and managing pressure injuries. In order to prevent their occurrence or worsening,
caregivers must conduct daily skin inspections, perform timely repositioning (e.g., pressure redistribution), encourage daily exercise routines into functional activities (e.g., standing when washing dishes), and monitor dietary intake (Houghton, Campbell & CPG, 2013). If the caregiver lacks the appropriate clinical knowledge and skills necessary to cope in a proactive and systematic manner with such caregiving tasks, it is probable that the individual with SCI will be at risk of pressure injury development (Elliot, Shewchuk & Richards, 1999). Furthermore, some individuals with paraplegia may be able to inspect their own skin, whereas individuals with a higher-level/complex injury (e.g., tetraplegia) require assistance from a caregiver (Houghton, Campbell & CPG, 2013). Given that family caregivers play a vital role in sustaining the care recipient’s overall wellbeing, intervention programs should be designed for caregivers to develop knowledge and skills in effectively preventing, detecting and managing secondary health conditions associated with SCI throughout the lifespan.

5.4.1 Limitations

Despite the strengths of the current study, a few possible limitations apply. Study limitations are linked to bias in the recruitment of participants. It is likely that those who decided to participate in the study may have been better adjusted than those individuals who declined participation (i.e., individuals who were recently injured or have been providing care for a short period of time). This may be a reason for an over-representation in the over 10 years post-discharge group as they have had more time to adapt to living with SCI or providing care. Within one year of injury is a crucial time for individuals with SCI and their family caregivers. It is evident that, at this stage of transitioning back to the community, both explicit and implicit needs arise from the individual with SCI, as well as the family members taking on the primary role of caregiver (Conti et al., 2016). Future research is needed on the types of support needed and the
factors associated with the need for more support for individuals who have recently been injured (i.e., within 1 year post-discharge). Furthermore, the needs of individuals with SCI and family caregivers may also have been driven by the specific health conditions experienced by the participants in our study. It should be noted that common health conditions such as peripheral neuropathy, neurological decline (secondary to a syrinx), and fracture, to name a few, did not emerge in our study despite their report in the literature.

5.4.2 Conclusion

This study is an important first step in advancing our understanding about the support needs of individuals with SCI. It highlights the complex care tasks that family caregivers provide and calls into question the role of the formal health care system in providing care to meet the needs of this population. Overall, the current study demonstrated that a higher level of injury, greater frequency of secondary health conditions (including but not limited to constipation and pressure injury), and age of the individual with SCI are indicative of needing more support from family caregivers, which includes practical, psychological and advocacy support. Considering the dramatic increase in the incidence of non-traumatic SCI over the coming two decades as a result of the aging population across Canada (Farry & Baxter, 2010), this population will likely require a high level and various types of assistance at home by family caregivers. The need for more caregiving support within the older SCI population due to the accompanying functional decline and injury-related health complications point towards development of timely and tailored interventions for this cohort. In addition, the current study identified various time points when individuals with SCI and their family caregivers require additional support from the healthcare system highlighting the need for more research on the role of paid caregivers and other
healthcare professionals. Future programs could be designed to address the support needs identified during these time points in an individual’s journey.
## Table 5.1: Characteristics of Participants in the Study

<table>
<thead>
<tr>
<th>Characteristics of Individuals with SCI</th>
<th>N=19</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>13</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td><strong>Time since discharge from inpatient rehabilitation (years)</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;2 years post-discharge</td>
<td>4</td>
</tr>
<tr>
<td>&gt;10 years post-discharge</td>
<td>15</td>
</tr>
<tr>
<td><strong>Level of injury</strong></td>
<td></td>
</tr>
<tr>
<td>Paraplegia</td>
<td>11</td>
</tr>
<tr>
<td>Tetraplegia</td>
<td>8</td>
</tr>
<tr>
<td><strong>Age (range; mean)</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>22-65; 45</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Characteristics of Family Caregivers</th>
<th>N=15</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>12</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>8</td>
</tr>
<tr>
<td>Unemployed/retired</td>
<td>7</td>
</tr>
<tr>
<td><strong>Relationship to Individual with SCI</strong></td>
<td></td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td>8</td>
</tr>
<tr>
<td>Parent</td>
<td>7</td>
</tr>
<tr>
<td><strong>Age (range; mean)</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>41-82; 61</td>
</tr>
</tbody>
</table>
Table 5.2: Summary of Types of Support Needed by Individuals with SCI, and Associated Examples

<table>
<thead>
<tr>
<th>Practical</th>
<th>Examples of Practical Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td>- Bathing</td>
</tr>
<tr>
<td></td>
<td>- Dressing</td>
</tr>
<tr>
<td></td>
<td>- Transferring</td>
</tr>
<tr>
<td></td>
<td>- Personal hygiene/grooming</td>
</tr>
<tr>
<td></td>
<td>- Bowel/bladder care (e.g. catheterization/digital stimulation/suppository)</td>
</tr>
<tr>
<td>Instrumental ADLs</td>
<td>- Preparing meals</td>
</tr>
<tr>
<td></td>
<td>- Housekeeping</td>
</tr>
<tr>
<td></td>
<td>- Transportation/driving</td>
</tr>
<tr>
<td></td>
<td>- Managing finances</td>
</tr>
<tr>
<td>Secondary Health Conditions Management</td>
<td>- Bowel dysfunction management (e.g. colostomy bag care)</td>
</tr>
<tr>
<td></td>
<td>- Bladder infection management (e.g. urinary tract infection, autonomic dysreflexia)</td>
</tr>
<tr>
<td></td>
<td>- Skin checks/pressure injury management</td>
</tr>
<tr>
<td></td>
<td>- Nutrition management</td>
</tr>
<tr>
<td></td>
<td>- Administration of medications</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emotional</th>
<th>Examples of Emotional Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moral Support</td>
<td>- Encouragement</td>
</tr>
<tr>
<td></td>
<td>- Confidence building</td>
</tr>
<tr>
<td></td>
<td>- Supporting CR personal autonomy</td>
</tr>
<tr>
<td>Support with Social Interaction/Integration</td>
<td>- Encouraging focus on CR’s personal/relational identity (i.e., taking on parental role)</td>
</tr>
<tr>
<td></td>
<td>- Empowering CR to be productive member of society (i.e., becoming a peer mentor)</td>
</tr>
<tr>
<td></td>
<td>- Encouraging CR to participate in recreational/leisure activities (e.g., adaptive sports or parasports)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Advocacy</th>
<th>Examples of Advocacy Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocate Support</td>
<td>- Understanding/being aware of CR’s needs/concerns</td>
</tr>
<tr>
<td></td>
<td>- Communicating and seeking solutions from healthcare professionals in a timely manner to get access to health and community services</td>
</tr>
</tbody>
</table>

CR, care recipient
Chapter 6

Identifying Required Skills to Enhance Family Caregiver Competency in Caring for Individuals with Spinal Cord Injury Living in the Community

Abstract

**Purpose:** Due to the earlier discharge of individuals with spinal cord injury (SCI), family caregivers are often left with limited time for learning caregiving skills, and usually feel unprepared to undertake the caregiver role. Considering the key role of family caregivers in maintaining the overall health and wellbeing of the individual with SCI, the objective of this study was to determine the breadth of skills needed by family caregivers to enhance their competency in caring for individuals with SCI living in the community.

**Methods:** A qualitative descriptive approach was used with semi-structured interviews. Thematic analysis was employed to determine key themes arising from individuals with SCI’s (n=19) and their family members’ (n=15) experiences.

**Results:** Twenty-nine SCI family caregiving skills were identified and grouped into six caregiving processes signifying the multiple dimensions of the SCI caregiving role. These include: monitoring and managing physical health and secondary health conditions; providing for psychosocial needs; decision-making; time management; being flexible; and navigating the health and social services system.

**Conclusions:** The current study demonstrated that development of multiple caregiving skills is crucial to enhance family members’ competency in caregiving. These findings should further alert healthcare professionals that assessment of caregiving skills at regular intervals is necessary to help caregivers achieve mastery in situations where they are facing caregiving difficulties.
Future programs need to be designed to include skills family caregivers need and use in real-life caregiving situations.
6.1 Introduction

The trend of decreasing length-of-stay in rehabilitation centres has resulted in individuals with spinal cord injury (SCI) entering the community with limited time for adjustment to the physical and psychological changes post-injury. They also have less time to obtain skills and knowledge to enhance their self-care abilities to be as independent as possible (McColl et al., 2012). Therefore, individuals with SCI commonly require assistance with a range of services from family members, that were previously provided by formal healthcare professionals (Schulz et al., 2009). Family members are often thrust into the caregiving role due to the sudden traumatic nature of the antecedent event (Baker et al., 2017). Moreover, due to the earlier discharge of individuals with SCI, family caregivers are also often left with limited time for learning caregiving skills, and are often unprepared to undertake these new time-consuming caregiver responsibilities (Robinson-Whelen & Rintala, 2003). Studies have demonstrated that caregivers of people with SCI can experience challenges and difficulties associated with providing long-term care (Nogueira et al., 2012; Post, Bloemen & de Witte, 2005).

Increasing attention has been given to understanding the negative effects of caring for an individual with SCI (Charlifue et al., 2016; Robinson-Whelen & Rintala, 2003; Gajraj-Singh, 2011; Dickson et al., 2010), with more recent studies examining possible predictors associated with caregiver burden (Post, Bloemen & de Witte, 2005; LaVela et al., 2015). Although research exploring predictors of caregiver burden contributes to our understanding of ways to protect family caregivers’ health and wellbeing; other aspects of family caregiving, such as understanding how care is provided and the required skills to sustain caregiving can also contribute to enhancing the overall quality of life (both objective and subjective health and well-being) of the caregivers as well as the care recipients. Family members who undertake
caregiving roles begin an “unexpected career” that is defined by the complex care they provide to their injured relatives (Aneshensel et al., 1995). Caregivers may need to carry out intricate medical tasks (Liem et al., 2004), organize/coordinate care tasks (Schumacher et al., 2000), and provide emotional support, direct care (e.g., wound care, transferring) (Post, Bloemen & de Witte, 2005) and advocacy (as mentioned in chapter 4). Such care entails a level of knowledge and skills unaccustomed amongst lay individuals (Dickson et al., 2010). One of the contributors to caregiver burden in SCI may be due to the lack of knowledge and resources, particularly skills training/development (Archbold et al., 1990).

The process of learning how to provide this care or acquiring proficiency in the necessary caregiving skills has been defined as “doing caregiving well” (i.e., becoming a competent caregiver) (Schumacher, Stewart & Archbold, 1998), and involves goal-directed and well-organized behaviours, which are acquired through practice. Caregivers differ in their level of “skillfulness” (Proctor & Dutta, 1995; Schumacher et al., 2000). Faran and colleagues (2004) described “more skilled family caregivers” (i.e., more competent caregivers) as having more flexibility and being less emotionally reactive; and “less skilled family caregivers” (i.e., less competent caregivers) have been characterized as more unyielding, having trouble adapting, and showing more severe emotional responses to caregiving situations.

Typically, when caregiving skill is mentioned, it is defined as skills specific to physical activities, tasks, or procedures (Schumacher et al., 2000). For example, skills needed by caregivers of individuals with SCI may include assistance with bowel and bladder management, meal preparation, pain management, and wound care (e.g., dressing, pressure redistribution). However, this perspective on caregiving is restricted to physical assistance; caregiving skills go beyond the capacity to provide physical support. Skills can be categorized as psychomotor (e.g.,
navigating obstacles with wheelchair), cognitive (e.g., monitoring, decision making, problem-solving), or psychological (e.g., providing emotional support/comfort) (Schumacher et al., 2000).

We found that lack of “necessary caregiving skills” was perceived as a key barrier to undertaking and sustaining the caregiving role (as mentioned in chapter 4). For example, not having necessary skills, such as being able to assess and interpret common symptoms associated with specific health conditions after SCI (e.g., recognizing the early symptoms of pressure injuries or autonomic dysreflexia), led to several challenges and consequences, such as worsening of the condition, increases in caregiver and care recipient anxiety, and frequent visits to the emergency department (as mentioned in chapter 4). Given and colleagues (2008) also identified the ability to communicate effectively with healthcare professionals as one of the most important caregiving skills. For example, family caregivers who are more competent in “working the system” are more likely to have their needs met.

The above research indicates that a skill-building approach, in addition to the traditional information only approach, is necessary for family members to provide sustained care to individuals with a SCI. However, little information is available about the caregiving skills that family caregivers of individuals with SCI require to provide care, nor do we understand how a lack of these skills may influence the care recipient’s health or trajectory in the health system. Also, the focus of rehabilitation services is directed towards self-management for the individuals with SCI; limited attention has been given to identifying the skill needs of family caregivers to provide care to individuals with SCI post-discharge. Given that family caregivers play a key role in maintaining the overall health and wellbeing of the care recipient with SCI, understanding the range of skills needed to undertake caregiving responsibilities can help identify possible strategies to assist family members to enhance their competency and perceived self-efficacy in
caregiving. Identifying the required skills can further decrease the negative consequences of providing care on the unprepared caregiver. The objective of this study was to determine the breadth of skills needed by family caregivers to enhance their competency in caring for individuals with SCI from the perspective of individuals with SCI and their family caregivers.

6.2 Methods

6.2.1 Design

To address the study objectives, a qualitative descriptive approach was utilized (Sandelowski & Barroso, 2003; Sandelowski, 2010), with the intent of understanding family caregiving skills in the ‘real world’. A qualitative approach can produce more exploratory information (Charlifue et al., 2016), particularly how caregiving challenges experienced and lessons learned translate into needed skills. Furthermore, the little that is known about caregiving knowledge and skills have typically been derived from studies of other disease populations (e.g., Alzheimer’s disease [Farran et al., 2003]), which although informative, may fail to capture crucial information that is specific to SCI caregivers (Charlifue et al. 2016). Therefore, a qualitative approach is the most appropriate research method to gather in depth information about the lived experiences of the caregivers and care recipients within their “natural context” (Sandelowski, 2000).

This descriptive qualitative study used data obtained in a larger study exploring the support needs of family caregivers of individuals with SCI. A brief overview of the methods is provided below; detailed procedures for the study are described in chapter 4. Ethics approval for study conduct was obtained from the University Health Network, and the University of Toronto. All participants in the study provided informed consent at the time of the interview.
6.2.2 Participants and Recruitment

Community-based individuals with SCI and their family caregivers were recruited from across Canada to participate. Taking into account the learning curve that occurs within the first two years, as well as the evolving needs of individuals with SCI over time, individuals who were at least 3 months to up to 2 years post-discharge and over 10 years post-discharge from inpatient rehabilitation were recruited. Caregivers/family members were recruited via the individuals with SCI and were acknowledged as his/her primary caregiver. Participants were recruited between August 2016 and April 2017. Recruitment ceased when the study reached the point of data saturation, whereby consecutive interviews did not yield new responses or thematic areas (Creswell et al., 2003).

6.2.3 Data Collection and Analysis

Data collection included separate semi-structured interviews through telephone or face-to-face interaction with caregivers and care recipients (please see Table 6.1 for a list of examples of open-ended questions from the interview guides). All interviews were audiotaped, transcribed verbatim, and reviewed for accuracy by the primary author.

The inductive thematic analysis procedures of open and axial coding, and extensive memo writing constituted the basic analytic techniques (Braun & Clarke, 2006). Qualitative software, NVivo 10 (Castleberry, 2014), was used to facilitate the organization and analysis of the data. Participants’ direct verbalizations of current and learned goal-directed behaviours used in caring for an individual with SCI, as well as the skills needed based on inferences that the authors made regarding the behaviours that might enhance a caregiving process constituted the units of analysis. Beginning with open coding, a subset of the transcripts was originally coded by
the primary author, and excerpts of the transcripts that described characteristics of family caregiving skill were highlighted. For example, using the analytic procedures described by Schumacher and colleagues (2000) as a guideline, caregivers’ accounts of how they managed specific health conditions (e.g., pressure injuries, autonomic dysreflexia, depression), procedures (e.g., intermittent catheterization, digital stimulation, administration of medication) (Schumacher et al., 2000), and barriers to caregiving (e.g., disruptive care recipient behaviour, role conflict) were initially examined. This approach enabled the identification of diverse skills used in caregiving and to determine areas of challenges (Schumacher et al., 2000). Examination of overlapping and contrasting data between care recipients and caregivers allowed for a global perspective that is more than the sum of the individual accounts. The identified skills were then grouped into broader categories that signify varying SCI family caregiving processes using the following criteria: similarities/differences, thematic overlaps, and redundancy of data. Two other researchers then independently coded the same subset of interviews and discussed the coding framework to refine existing categories. This ensured rigor and enhanced reflexivity. To increase trustworthiness and credibility, four members of the research team participated in ongoing peer debriefing sessions to discuss the analysis, interpretation of data, and development/consensus of theme labels.

6.3 Results

6.3.1 Description of Participants

A total of 34 interviews were conducted, including 19 individuals with SCI and 15 family caregivers. From the 34 participants, 26 individuals were in dyads (13 caregiver-care recipient dyads), as well 2 caregivers and 6 care recipients were also interviewed. Demographic
characteristics of the care recipients and caregivers are described in Table 6.2. Approximately 75% of the caregivers had been providing care for more than 10 years, while the remaining had only been in the role for 6 months to 2 years.

6.3.2 SCI Family Caregiving Skills

Twenty-nine SCI family caregiving skills were identified and grouped into six caregiving processes (Table 6.3). In the current study, caregiving processes are defined as dimensions of the SCI caregiving role which require a course of action. The results are presented according to the caregiving processes and associated skills (presented as [skill]), with representative quotations that highlight important points.

6.3.2.1 Monitoring and Managing Physical Health and Secondary Health Conditions

Caregivers require skills related to observing and appraising changes in the care recipient’s physical, behavioural or emotional condition to prevent or treat as early as possible the symptoms associated with secondary health conditions associated with SCI or aging. The majority of participants described skills in monitoring and managing the care recipients’ physical condition, particularly secondary health conditions associated with SCI. For example, one caregiver shared how instead of seeking explanations for unknown signs and symptoms [skill] at the start of a pressure injury, she attributed the change in skin integrity incorrectly, to a “pimple”. The more competent caregivers took initiative to pay attention to detail/subtle physical changes to avoid worsening of symptoms: “So, I check anyway, if there are any red marks, usually on her butt” (CG 5, mother). Several caregivers further added that they had to also learn to use devices to monitor health [skill] and appraise the changes in the care recipients’ physical health: “I got one of those little things [blood glucose test meter], I test his blood about...
every second day so his sugar is down to under 6 and it's okay because he was up to 13.5 which is really high” (CG 8, mother).

To manage changes in the care recipients’ physical health, caregivers extensively used medication and nutrition management skills. They reported ‘keeping track of and administering medication’ was a skill routinely used: “I get his pills ready for seven days and I have a little dispenser and I just give him his pills, like morning, lunch time, supper time and night time” (CG 8, mother). Few older participants reported that the caregivers had further developed the [skill] of managing multiple illness care needs of the care recipients simultaneously due to comorbidities associated with aging. In the context of medication management, one caregiver described her skill in managing medications for her partner who had both a SCI and dementia:

“I make sure that he has his medications on time when he’s supposed to, because he has the beginning part of Alzheimer’s. It’s not as bad as what it is going to get, but he does frequently forget and so I keep reminding him. And, if I’m not there, I phone him constantly, and at the times that I know he is supposed to have his medication and make sure he’s taking it.” (CG 13, partner)

The importance of having the [skills] for administering nutritional intake and ensuring proper nutrition to manage neurogenic bowel dysfunction was emphasized:

“I constantly have to be aware that he does get constipated from the medication. I have to get a lot of greens into him and stuff that will make him go to the bathroom that I know moves him.” (CG 15, mother)
Providing for Psychosocial Needs

Caregivers require skills related to ensuring the psychological, social, and spiritual needs of the care recipient are recognized and met. In describing how they attended to the psychosocial needs of their family members, caregivers reported using a broad range of skills that they acquired throughout the years through personal interactions with the care recipients. The more competent caregivers learned to maintain a sense of humour and spirituality [skill] and guide with patience [skill] to avoid escalating care recipients’ distress and anxiety levels:

“Like if he’s supposed to go on an appointment somewhere, and I call and I say are you ready for the appointment today? And he said what appointment? And then I’ll tell him. And, oh, I forgot. I say that’s okay, don’t worry about it. Just get ready and go, because I’ll be checking with you and make sure you have gone. And he says, okay, fine, thank you for calling. I appreciate that. So, this is it, is to be relaxed, have the patience...” (CG 13, partner)

Both caregivers and care recipients emphasized the importance of maintaining care recipient’s dignity [skill] when providing care. Several participants commented on the importance of ensuring privacy when providing care, such as: closing washroom doors during bowel and bladder care, giving thought to helping the care recipient with their personal appearance, asking the care recipient how he/she would like to be dressed. Few care recipients stated the importance of respecting their decisions when providing care:

“I think I’ve seen it in others, in other quads that I’ve known, where people forget that they are dealing with adults that want to make their own decisions, that want to have some degree of privacy, as much as they can have it.” (CR 20, husband)
In addition, a few caregivers further explained that respecting the care recipients’ decision in self-care tasks empowered their autonomy.

Caregivers continued to use similar skills to manage the care recipients’ psychological and behavioural changes. Caregivers reported providing positive coping strategies [skill] intended to reduce the stress levels of their loved ones. For example, one caregiver shared how she would encourage her son to spend some time away when he is showing signs of sadness or frustration: “When he gets fed up I’ll say well let’s go out and I’ll put him in the van. We might go down to Vaughan Mills [shopping centre] just to get change of [atmosphere]” (CG 8, mother), whereas, another caregiver learned to distract her husband when he is agitated during bowel care: “I feel like sometimes I’m playing a game with him just to distract him. I’ll start a conversation as I’m doing it just so that maybe he’ll talk about something different so that he can get it done” (CG 2, wife).

A number of caregivers added that in order for their family members with SCI to have satisfying social lives relative to their pre-injury status and not feel restricted in social activities, they ensured social interaction and integration [skill]. Several examples of social interaction and integration reported by caregivers include recreational pursuits (e.g., parasports), community participation (e.g., peer support groups), and interpersonal interactions (e.g., building healthy relationships with family and friends). One caregiver shared his experience of encouraging participation in recreational activities as a couple:

“We purchased an adapted bicycle, which kind of clasps onto her wheelchair and it’s one of these bikes which is hand-driven...So, we’re doing it still in many ways in a perhaps slightly more curtailed circumstance, but she’s doing it...So, we’re doing it now.” (CG 6, husband)
### 6.3.2.3 Decision-Making

Decision-making requires skills related to selecting a logical choice based on the caregiver’s careful examination, consideration, and interpretation of the caregiving situation. For this caregiving process, we focused on caregiving decisions related to activities of daily living (ADLs). Although decision-making is a continuous trial and error process, the more competent caregivers were able to choose a course of action that did not compromise the quality of care to the care recipients. For example, such caregivers mastered the [skill] of considering possible consequences of a decision and modifying the decision as needed to reduce the risk of harm to the care recipients:

“The bed, safety-wise, has got to have a rail on it so that they don’t fall out because [care recipient] could have muscle spasms, even, in her sleep and that could make her fall out of bed. Now, I realize, okay, we have got to have a side up on the bed.” (CG 5, mother)

Role conflict was mentioned as a notable barrier to providing care to individuals with SCI. However, several participants had reported that the caregivers had acquired the [skill] of assessing the importance of conflicting roles in order to manage day-to-day care tasks effectively. One care recipient shared an experience of how her mother assessed conflicting roles (i.e. deciding to attend to the caregiver role or social/relational role):

“A couple of weeks ago my grandfather ended up in the hospital by mom couldn’t go [attend to him] because she was here with me, and the lady [third party caregiver] was away...And then mom didn’t want to take me up to the hospital with her because everyone is sick up there and she didn’t want me to get sick and be stuck sitting up there all evening.” (CR 17, daughter)
Some participants explained that they had become completely engrossed in the caregiving role. While the less competent caregivers continued to take responsibility for all caregiving tasks, the more competent caregivers learned when to step back from caregiving tasks [skill], as well as when to seek informal social support [skill]. The following caregiver demonstrates effective decision-making as she not only considered when to minimize her caregiving involvement, but she also took an incremental approach in stepping back from caregiving tasks:

“*She said if she couldn’t learn the proper way, then she wasn’t going to eat. So, I just put it in her fingers at first, lifted it through, and she learned to get it up there herself and now she can pick it up herself and do it.*” (CG 5, mother)

6.3.2.4 Time Management

Time management consists of skills related to using time effectively and productively to achieve multiple caregiving tasks. The majority of participants reported that caregivers used time efficiently to reduce short-term strain resulting from role overload by planning ahead [skill] and developing a routine to manage caregiving tasks [skill]. The following participant demonstrated the importance of planning ahead and developing a routine to reduce role conflicts (e.g., work-life balance):

“If it’s a bowel routine morning, then I put in the enema, I help him get on his commode chair and then he wheels himself to the bathroom. And then I give him 20 minutes or so. It’s the same thing every morning...I make his lunch the night before. There’s always a lunch in the fridge during the school year. I’m a teacher. So, during the school year there’s always a lunch in the fridge.” (CG 2, wife)
On the basis of our analysis of skills that might enhance competency in caregiving, we inferred that caregivers would benefit from developing the [skill] of timing daily activities according to the care recipient’s care needs, such as the frequently mentioned task of performing intermittent catheterization. This skill would focus on proactively anticipating the care recipient’s daily rhythm (e.g., urinary voiding patterns) and more adeptly managing daily tasks around the needs of the care recipient.

### 6.3.2.5 Being Flexible

Being flexible consists of skills related to actively and continuously improving caregiving actions until an effective strategy/solution is identified to address the evolving caregiving situation. Being flexible is a continuous process and requires frequent adjustments, and family caregivers often reported they developed these skills through trial and error. Participants repeatedly emphasized that the caregivers were able to quickly acquire the [skill] of modifying the house or environment to accommodate the care recipients’ needs, particularly soon after discharge from inpatient rehabilitation. Several care recipients stated that the transition back home was smooth due to the house being adapted prior to discharge.

The more competent caregivers had a keen ability to stay attuned to the dynamic caregiving situations by persistently trying multiple strategies until solution is found to caregiving challenges [skill], learning from mistakes [skill], as well as finding alternative caregiving methods [skill]. A number of caregivers stated that it is imperative to possess these skills for several reasons: when the original caregiving method no longer worked, to identify the best caregiving method for different situations, to enhance the quality of care for the care recipients, and to ensure efficient caregiving. As one care recipient reported:
“Skills are [finding] the easiest possible way to move me without my legs kicking and going, and how to get me in and out of the bathtub, how to get me dressed and things like that, we learned the easiest possible way.” (CR 18, daughter)

A common caregiving challenge for which solutions were usually temporary was meal planning. The more competent caregivers described using creativity to solve caregiving challenges [skill]. For example, several caregivers took initiative to create their own recipes considering the recommended healthy diet and the care recipients’ individual food preferences:

“You’re used to living a certain lifestyle before something like this happens and there are some foods you don’t know. He [care recipient] doesn’t like them. I try and make smoothies with juices. I’m working on trying to give him some smoothies. I just have to be very flexible because people get sick of eating the same thing all the time...I’ve tried to be aware of that. I think the food management is a difficult thing, but I just keep working away at it.” (CG 8, mother)

6.3.2.6 Navigating the Health and Social Services System

Navigating the health and social services system includes skills related to accessing health care and social services, and ensuring that the care recipient’s care needs are met appropriately. Due to the fact that this caregiving process was mentioned as one of the challenging aspects of caregiving and many individuals, particularly soon after discharge, had difficulty navigating the system, we inferred that caregivers would greatly benefit from developing [skills] such as seeking medical assistance from healthcare professionals in a timely manner. For example, a number of caregivers often questioned whether the appearance of new symptoms related to secondary health conditions were severe enough to seek professional help.
In addition, it is also imperative to assess the care received in the healthcare system [skill] and advocate for the care recipient when necessary [skill]. For example, by assessing the self-management techniques that were provided by the nurses to her injured daughter, a mother (and in agreement with her daughter) recognized these techniques were more general and not tailored to her daughter’s abilities. The caregiver took initiative to voice her daughter’s concern to the healthcare professionals to address this issue. Several participants had reported that the caregivers needed to learn additional skills in order to enhance caregiving, particularly how to actively seek resources and information [skill]. Resources included effective assistive devices, and information was described as diligently updating caregiving techniques (through training or making careful observations during rehabilitation). This skill focuses on using creative ways to tap into available resources (e.g., home care, assistive devices, funding programs) in order to adequately meet the care recipient’s needs.

Just as it is important to seek assistance from healthcare professionals, it is also imperative to know when to seek supportive care when needed [skill], such as that of paid third-party caregivers (e.g., personal support workers [PSW]). A number of caregivers quickly learned how to navigate the home and community services system and described how they were able to receive practical support (e.g., support with self-care tasks) by a hired PSW or attendant. Nonetheless, several caregivers found PSWs sometimes created added stress and some were dissatisfied with the quality of care provided by PSWs. Indeed, the caregivers had to acquire the skill of learning to provide training to third-party caregivers [skill] on how to provide care, that met the needs of the care recipient:

“I found that as we started getting PSWs in and support for [care recipient], I’m still the person that trains them. They sometimes come in not knowing what to do...because there
are certain things that certain agencies don’t allow their PSWs to do, so I fill in those gaps.” (CG 2, wife)

6.4 Discussion

The current study aimed to determine the breadth of skills needed by family caregivers to enhance their competency in caring for individuals with SCI from the perspectives of individuals with SCI and their family members. Using a qualitative descriptive approach, twenty-nine SCI family caregiving skills were identified and grouped into six caregiving processes signifying the multiple dimensions of the SCI caregiving role. The findings from our study provide insight into the range of skills that could inform the development of interventions to help caregivers increase competency and perceived self-efficacy in caregiving. As a result, having these skills could decrease the stress level of both the individuals with SCI and family caregivers, as well as help maintain the health and wellbeing of the individuals with SCI in the community.

Our findings make substantive contributions to our understanding of the linked notions of family caregiving skill and competency among caregivers of individuals with SCI. Studies in other disease populations have described the caregiving processes of decision making (Sims et al., 1992; Schumacher et al., 2000), monitoring and assessing (Albert, 1993; Brown & Powell-Cope, 1991), and accessing available resources (Paun et al., 2004; Robinson, Adkisson & Weinrich, 2001). However, in comparison to caregivers of individuals living with other chronic illnesses and injuries, caregivers of individuals with SCI face unique challenges, such as: 1) providing care specifically linked to SCI-related health conditions (e.g., constant pressure injury monitoring and management, monitoring of fluid and fibre intake for bowel and bladder) (Nogueira et al., 2012); 2) the duration of the caregiving period (Schulz et al., 2009); 3) the
functionality of the individual with SCI, which does not improve over time (Dickson et al., 2010); and 4) the unique challenges brought about by the interactions of aging, impairment and multimorbidity (Schulz et al., 2009). As a result, family caregivers of individuals with SCI are required to continuously develop and refine caregiving skills in order to address these challenges unique to SCI. These caregiving skills are acquired through time and with experience (Paun et al., 2004), commonly through trial and error. Our study findings highlight the complex nature of the caregiving role in SCI.

Previous studies have reported that caregivers of individuals with SCI receive some basic information on providing care post-discharge, such as practical caregiving information (Munce et al., 2014; Conti et al., 2016) (e.g., bowel and bladder management). However, the current study supports Schumacher and colleagues’ (2000) findings that caregiving is not a straightforward approach encompassing the willingness to follow a set of guidelines and instructions. Indeed, our data suggest that caregivers require higher-order thinking skills, such as the ability to monitor and assess symptoms related to secondary health conditions following a SCI, which may entail symptom recognition, complex reasoning and problem-solving. The most frequently mentioned secondary health condition associated with SCI was pressure injuries. In order to prevent the occurrence or worsening of pressure injuries, or to facilitate pressure injury healing, caregivers must use a combination of skills in conducting daily skin inspections, performing timely repositioning (e.g., pressure redistribution), encouraging daily exercise routines into functional activities, and monitoring dietary intake (Houghton, Campbell & CPG, 2013) based on each care recipient’s individual health needs and concerns. It should be noted that some individuals with paraplegia may be able to inspect their own skin; however, individuals with a higher-level/complex injury, such as tetraplegia, require assistance from a caregiver (Houghton,
In the case where the individual with SCI is unwell or unable to inspect his/her own skin, and the caregiver lacks the higher-order thinking skills necessary to cope in a proactive and systematic manner with the multiple demands of caregiving, it is probable that the care recipient will be at risk of pressure injury development (Elliot, Shewchuk & Richards, 1999). In fact, the caregivers in our study described the challenges and consequences of not having such skills for symptom assessment and management of pressure injuries and autonomic dysreflexia, such as worsening of the complication, increase in care recipient and caregiver distress, and frequent visits to the emergency department. These findings were corroborated by a quantitative study conducted by Elliott, Shewchuk and Richards (1999) who determined that poor problem-solving abilities among caregivers correlated with the occurrence of pressure injuries and adjustment challenges within individuals with SCI during the early phase of the injury. In this regard, family caregiving skills need to involve active problem-solving and decision-making, instead of a passive response to care challenges (Schumacher et al., 2000).

While previous studies focusing on family caregiving skills within other disease populations, such as Alzheimer’s disease (Paun et al., 2004; Farran et al., 2003) and cancer (Schumacher et al., 2000), have mentioned various skills associated with managing the physical health of the care recipients, the current study further highlighted important skills in managing the psychosocial health of the individual with SCI. These skills contribute to the overall wellbeing of the care recipient and ensured the maintenance of the recipient’s respect, privacy, choice, dignity, and control (Walsh & Kowanko, 2002). Our data further suggest that caregivers develop such skills through affective relationships with the care recipients that foster a deeper understanding about the care recipients’ psychosocial needs. These data support the notion that
the combination of both knowledge and a synergistic interaction, which includes understanding and acceptance of specific characteristics/trait of the caregiver and care recipient as individuals (e.g., maintaining a sense of humour and spirituality, understanding the need to provide care with respect and dignity) as well as a dyad (e.g., dyadic social interaction, or knowing when to step back from caregiving tasks to allow for care recipient’s autonomy), is essential to successful skill development over time.

Central to this knowledge is the recognition that family caregiving skill is varied, such that caregivers might be more competent in some aspects of caregiving and less competent in other aspects- there is no “perfect caregiver.” More competent caregivers were often aware of and have a greater understanding of their family members’ needs (Paun et al., 2004). They were sensitive to the complexity of the injury and the caregiving process. This understanding and sensitivity translated into behaviours that enhanced care recipient outcomes (Farran et al., 2003). These behaviours included taking initiative to effectively and efficiently integrate knowledge in monitoring and managing the physical and mental health needs of the care recipient, using higher-order thinking skills to make day-to-day care decisions, handling multiple demands of caregiving, ensuring flexibility in their actions, and working the system in order to meet the care recipient’s needs. Less competent caregivers’ knowledge and insights were more limited (Farran et al., 2003). They had difficulty dealing with change, learning new information, transforming their behaviour to different caregiving situations, learning to use resources more widely, as well as making choices that put the care recipient at risk for harm.

The following section outlines suggestions to move this knowledge of SCI family caregiving skills forward. The most evident gap in current caregiver interventions is lack of an approach to assess the breadth of real-life caregiving skills (Bourgeois, Schulz & Burgio, 1996).
Current measures assess SCI caregiver’s perception of personal coping skills (Dickson et al., 2012; Beauregard & Noreau, 2009; Rivera et al., 2008; Backhaus et al., 2010), but do not assess the caregiver’s actual level of skill in providing care to the individual with SCI. Indeed, concerted efforts are required to assist family caregivers to develop and refine the skills needed to care for individuals with SCI, and, thus far, interventions have not addressed this issue (Charlfue et al., 2016; Given et al., 2008). The findings from our research suggest an approach similar to clinical assessment whereby healthcare professionals could conduct initial and ongoing assessments to determine each caregiver’s level of skill and target interventions according to the caregiver’s learning needs. For example, healthcare professionals could assess caregivers’ abilities to recognize/assess the early symptoms of pressure injuries and provide guidance as needed. Our results further suggest that intervention programs should be designed to meet the changing needs of family caregivers over time. This could enhance their necessary skills and assist caregivers to obtain mastery in situations where caregivers feel challenged. This would be in contrast to the current system where short periods of instructions are provided by healthcare professionals during inpatient rehabilitation or, as mentioned in chapter 4, the more commonly provided general information (particularly in written format). However, further research conceptualizing SCI family caregiving skill are needed prior to designing a standardized assessment tool.

In addition, the findings from the current study suggest that family caregivers assume responsibility for intricate and complex caregiving tasks, specifically medical related, such as monitoring and managing physical health and secondary health conditions; however, questions remain as to the extent to which family caregivers should provide such support, in lieu of formal caregivers (e.g., nurses, PSWs). The responsibility for ensuring that the health care needs of the
individuals with SCI are met does not rest solely with family caregivers; the findings from the current study initially point towards the need for a collaborative effort. We suggest a collaborative approach-whereby healthcare professionals, formal caregivers, and family caregivers work together-to better meet the needs of the individuals with SCI and be partners in patient care.

6.4.1 Limitations

Despite the strengths of the current study, a few possible limitations apply. First, the method used for recruitment of participants may have resulted in bias. It is possible that those individuals who decided to participate may have been better adjusted to the caregiving role and were more competent than those individuals who declined participation. This is perhaps a likely reason for an over-representation in the over 10 years post-discharge group as they have had more time to adjust to living with SCI or providing support. Also, it is possible that the individuals with SCI in our study may have considerable medical morbidities and have complex or high caregiving needs. Finally, the majority of participants were primarily Caucasian working/middle-class. Future research should be directed towards examining the experiences and skill needs of family caregivers from other cultural and ethnic groups, and the impact of sociocultural factors on family caregiving skill development.

6.4.2 Conclusion

Overall, the current study demonstrated that development of multiple caregiving skills is crucial to enhance family members’ competency in caregiving. Furthermore, considering the evolving health care needs of the individual with SCI, the findings from the current study suggest a greater involvement of healthcare professionals in assessing caregiving skills at regular
intervals. Such assessments can help family caregivers identify areas to develop the necessary skills and achieve mastery in situations where they are facing caregiving difficulties. These findings should further alert healthcare professionals that skill development is a complex and dynamic process consisting of learning, applying knowledge and behavior changes that require practice and consistent support over time. In addition, program planners and policy makers, along with healthcare professionals, must also work together to provide the necessary support services needed by family caregivers, as they are an important national healthcare resource. Despite ample research suggesting the need to improve caregiving knowledge and skills (Charlfue et al., 2016; Archbold et al., 1990), there continues to be lack of evidence-based interventions that include skills family caregivers need and use in the real-life caregiving situations. Therefore, the breadth of skills needed by family caregivers to provide care to individuals with SCI can inform the design of programs that focus on enhancing caregiver competency.
Table 6.1: Examples of Open-Ended Questions from Interview Guides for SCI Family Caregiving Skills

1. Caregiver: What are some skills you currently use or have developed over time in assisting your family member (can you please provide some examples)?

2. Caregiver: Considering the skills you have to care for your family member, what are some consequences or challenges you are facing by not necessarily having all of the appropriate skills?

3. Care recipient: What are some skills you feel your family member would benefit from learning to be able to provide better care for you?

4. Care recipient: Was there any incident where your family member felt a certain caregiving task was difficult to do? Why?
Table 6.2: Characteristics of Participants in the Study

<table>
<thead>
<tr>
<th>Characteristics of Individuals with SCI</th>
<th>N=19</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>13</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td><strong>Time since discharge from inpatient rehabilitation (years)</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;2 years post-discharge</td>
<td>4</td>
</tr>
<tr>
<td>&gt;10 years post-discharge</td>
<td>15</td>
</tr>
<tr>
<td><strong>Level of injury</strong></td>
<td></td>
</tr>
<tr>
<td>Paraplegia</td>
<td>11</td>
</tr>
<tr>
<td>Tetraplegia</td>
<td>8</td>
</tr>
<tr>
<td><strong>Age (range; mean)</strong></td>
<td>22-65; 45</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Characteristics of Family Caregivers</th>
<th>N=15</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>12</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>8</td>
</tr>
<tr>
<td>Unemployed/retired</td>
<td>7</td>
</tr>
<tr>
<td><strong>Relationship to individual with SCI</strong></td>
<td></td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td>8</td>
</tr>
<tr>
<td>Parent</td>
<td>7</td>
</tr>
<tr>
<td><strong>Age (range; mean)</strong></td>
<td>41-82; 61</td>
</tr>
</tbody>
</table>
Table 6.3: SCI Family Caregiving Processes and Skills

<table>
<thead>
<tr>
<th>Caregiving Processes</th>
<th>Caregiving Skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitoring and Managing Physical Health &amp; Secondary Health Conditions</td>
<td>a. Seeking explanations for unknown signs &amp; symptoms</td>
</tr>
<tr>
<td></td>
<td>b. Paying attention to detail/subtle physical changes</td>
</tr>
<tr>
<td></td>
<td>c. Using devices to monitor health</td>
</tr>
<tr>
<td></td>
<td>d. Keeping track of and administering medication</td>
</tr>
<tr>
<td></td>
<td>e. Managing multiple illness care needs of CR simultaneously (e.g., other comorbidities)</td>
</tr>
<tr>
<td></td>
<td>f. Administering nutritional intake/ensuring proper nutrition</td>
</tr>
<tr>
<td>Providing for Psychosocial Needs</td>
<td>a. Maintaining a sense of humour or spirituality</td>
</tr>
<tr>
<td></td>
<td>b. Guiding with patience</td>
</tr>
<tr>
<td></td>
<td>c. Maintaining CR dignity</td>
</tr>
<tr>
<td></td>
<td>d. Providing positive coping strategies</td>
</tr>
<tr>
<td></td>
<td>e. Ensuring social interaction/integration</td>
</tr>
<tr>
<td>Decision-Making</td>
<td>a. Considering possible consequences of a decision and modifying decision as needed</td>
</tr>
<tr>
<td></td>
<td>b. Assessing the importance of conflicting roles</td>
</tr>
<tr>
<td></td>
<td>c. Deciding when to step back from caregiving tasks</td>
</tr>
<tr>
<td></td>
<td>d. Deciding when to seek informal social support</td>
</tr>
<tr>
<td>Time Management</td>
<td>a. Planning ahead to manage caregiving tasks</td>
</tr>
<tr>
<td></td>
<td>b. Developing a routine to manage caregiving tasks</td>
</tr>
<tr>
<td></td>
<td>c. Timing daily activities according to CR’s care needs</td>
</tr>
<tr>
<td>Being Flexible</td>
<td>a. Modifying house/environment to accommodate CR’s needs</td>
</tr>
<tr>
<td></td>
<td>b. Trying multiple strategies until solution is found to caregiving challenges</td>
</tr>
<tr>
<td></td>
<td>c. Learning from mistake</td>
</tr>
<tr>
<td></td>
<td>d. Finding alternative caregiving methods</td>
</tr>
<tr>
<td></td>
<td>e. Using creativity to solve caregiving challenges</td>
</tr>
<tr>
<td>Navigating the Health &amp; Social Services System</td>
<td>a. Seeking medical assistance from healthcare professionals in a timely manner</td>
</tr>
<tr>
<td></td>
<td>b. Assessing care received in the healthcare system</td>
</tr>
<tr>
<td></td>
<td>c. Advocating for the CR when necessary</td>
</tr>
<tr>
<td></td>
<td>d. Actively seeking resources/information</td>
</tr>
<tr>
<td></td>
<td>e. Seeking supportive care when needed</td>
</tr>
<tr>
<td></td>
<td>f. Providing training to third-party CGs</td>
</tr>
</tbody>
</table>

CR, care recipient; CG, caregiver
Chapter 7

Re-building Relationships after a Spinal Cord Injury: Experiences of Family Caregivers and Care Recipients

Abstract

Purpose: Following spinal cord injury (SCI), family members are often called upon to undertake the caregiving role. This change in the nature of the relationship between the individuals with SCI and their families can lead to emotional, psychological, and relationship challenges. Thus, the objectives of this study were to obtain an in-depth understanding of 1) the experiences and challenges within a caregiving relationship post-SCI among spouses, as well as parents and adult children; and 2) how caregivers and care recipients negotiate changes within the relationship.

Methods: A qualitative descriptive approach was used with semi-structured interviews. Thematic analysis was employed to determine key themes arising from individuals with SCI’s (n=19) and their family members’ (n=15) experiences.

Results: The following four factors that challenged relationship stability were identified: protective behaviours, asymmetrical dependency, loss of sex and intimacy, and difficulty adapting. Conversely, the following four strategies used by care recipients and caregivers to maintain/re-build their relationships were identified: interdependence, shifting commonalities, adding creativity into routine, and creating a new normal.

Conclusions: These findings should alert healthcare professionals and peer support groups as to the need for possible education and training (e.g., coping strategies, communication skills training) as well as counseling prior to discharge to assist individuals with SCI and family caregivers with adaptation to new life post-injury.
7.1 Introduction

Following spinal cord injury (SCI), spouses and other family members are often called upon to undertake the caregiving role (Post, Bloemen & de Witte, 2005). Accordingly, changes in the nature of the relationship (e.g., role change from spouse to caregiver) between the individuals with SCI and their families can put the family dynamics at risk (Charlifue et al., 2016) and challenge the family physically, psychologically, and socially (Middleton et al., 2014). Comparable to the individuals with SCI, the family caregivers are often required to reconstruct their lives, as well start an ‘unexpected career’ to provide support with activities of daily living (ADLs), personal care, and emotional support to their family member with a disability (Archbold et al., 1990; Dickson et al., 2010).

The stress associated with assuming the caregiving role (Chan, Lee & Lieh-Mak, 2000) can influence the adjustment of individuals with SCI and their families (DeSanto-Madeya, 2009). Cleveland (1980) determined that tasks associated with caring for an individual with SCI were often unevenly distributed amongst family members, thereby resulting in increased stress in communication, family unity, family power structure, and interpersonal relationships. With respect to partner relationships, DeVivo and Fine (1985) explored the impact of SCI on the marital status of 276 injured individuals for a 3-year period post-injury. They found a significantly higher incidence of divorce and separation during the first 3 years after the injury, indicating it was very demanding trying to rebuild daily life and relationships during the early stage of the injury (DeVivo & Fine, 1985). The authors also reported that women with SCI are more likely to be divorced than men. In a later study, DeVivo and Richards (1992) determined that among the individuals who were married at the time of their injury, 81 percent were still married 5 years later. In another study conducted by Kreuter and colleagues (1998), findings
showed that challenges in adapting to new physical functions, unwillingness to live with the injured individual, and difficulties in maintaining the relationship resulted in divorce post-injury. The authors highlighted the importance of the partners’ mutual support and the significance of maintaining a marriage/relationship (Kreuter et al., 1998).

Emerging literature on dyadic coping between caregivers and care recipients provides insight into how couples manage health, relational, and psychosocial issues (Bodenmann, 2005; Story & Bradbury, 2004; Berg & Upchurch, 2007). Among those who had coronary artery bypass surgery or heart attack, Goldsmith (2004) reported that dyadic coping strategies such as daily conversations, routines and shared activities with a caregiver can facilitate the care recipient’s recovery. However, it is imperative to recognize that, within each relationship, couples may experience the effects of the illness or injury differently (Berg et al., 2008; Checton, Greene, Magsamen-Conrad, & Venetis, 2012). Another recent study by Keesing, Rosenwax and McNamara (2016) took a dyadic approach to understanding the impact of breast cancer on relationships and how partners maintained relationships during early survivorship. The participants in that study stated that concentrated effort was required by partners to understand and respect each others’ needs by utilizing open communication and empathy skills. Although these studies provide valuable insight into the nature of caregiving relationships, the extent to which these findings can be generalized to individuals with SCI and their family caregivers is unknown. Indeed, providing care to individuals with SCI is distinct from other illnesses and injuries due to the unique challenges of providing care related to the complications associated with SCI (e.g., bladder and bowel problems, and pressure injury management [Nogueira et al., 2012], and the longer duration of their caregiving period [Schulz et al., 2009]).
While previous studies have focused on the impact of SCI on relationships (McGowan & Roth, 1987; DeSanto-Madeya, 2009; Angel & Buus, 2011), these studies used quantitative methods to examine marital status, long-term marital survival, and the impact of SCI on the relationship from the perspective of the individual with SCI (Dickson et al., 2010). Furthermore, these studies only highlighted the negative impact on relationships. There is limited research on how individuals with SCI and their family caregivers adapt to their new lives post-injury, or on which dyadic adaptation or interactions are used to maintain adaptive relationships or positive dyadic coping. Furthermore, when an individual is younger (i.e., young adult) and not married, the role of caregiving most often falls to the parents. Yet, there is a paucity of published literature on parents as caregivers and the impact of SCI on the parent-child relationship. As a result, there is an increased need for qualitative research examining partner/parent relationships post-injury. Thus, the objectives of this paper were to obtain an in-depth understanding of 1) the experiences and challenges within a caregiving relationship post-SCI among spouses, as well as parents and adult children; and 2) how caregivers and care recipients negotiate changes within the relationship.

### 7.2 Methods

#### 7.2.1 Design

A qualitative descriptive study was undertaken (Sandelowski & Barroso, 2003; Sandelowski, 2010) as there are limited studies examining the relationship between individuals with SCI and their family caregivers. Thus, a qualitative approach contributed to our understanding about the lived experiences of the caregivers and care recipients within their “natural context” (Sandelowski, 2000). The data used in the current study were based on qualitative interviews conducted by the primary author for a larger study exploring the support
needs of family caregivers of individuals with SCI. Detailed methods for the study have been described in chapter 4. During the interviews, topics related to the impact of SCI on relationships emerged in the dialogue of the participants. The insights that emerged during the early interviews were then introduced to subsequent interviews and new themes were identified based on the participants’ responses. Research ethics approval was obtained from the University Health Network and the University of Toronto. All participants provided their informed consent at the time of the interview.

7.2.2 Participants and Recruitment

Individuals with SCI living in the community across Canada and their family caregivers were recruited to participate in the current study. Family members were recruited via consenting individuals with SCI who identified the individuals as their primary caregiver. Participant recruitment occurred between August 2016 to April 2017. Recruitment concluded when the study reached data saturation, whereby successive interviews became repetitive and no new responses/themes emerged (Creswell et al., 2003).

7.2.3 Data Collection and Analysis

Data collection consisted of semi-structured interviews through telephone or face-to-face interaction (please see Table 7.1 for a list of examples of open-ended questions). Probes or recursive questioning were used during interviews to explore topics in greater depth (Patton, 1990) and to enable the participants to share any experiences they felt were crucial to the study. All telephone and face-to-face interviews were audiotaped, transcribed verbatim, and reviewed for accuracy.
The inductive thematic analysis procedures of open and axial coding, and comprehensive memo writing constituted the basic analytic techniques (Braun & Clarke, 2006). Qualitative software, NVivo 10 (Castleberry, 2014), was used to organize and analyze the data. Considering the potential variability in the level of support provided when taking care of an individual with SCI by different family members, analysis was stratified based on caregiver relationship (i.e., spouses and parents). Starting with open coding, a subset of the transcripts were initially coded by the primary author, and a ‘description’ was assigned for each event, idea, or phenomena discussed by each participant using an inductive approach. For example, excerpts of the transcripts that described the challenges experienced that caused a deterioration in relationships post-injury, as well as strategies (i.e., behaviours and actions) used by caregivers and care recipients in maintaining/re-building their relationships were initially examined. Overlapping and contrasting data between care recipients and caregivers were then grouped. This ensured a global perspective that is more than the sum of the individual accounts. Subsequently, codes were clustered into categories and apparent themes were identified. Two independent researchers further coded the same transcripts to enhance the reflexivity and rigor of the study. In addition, four members of the research team had ongoing peer debriefing meetings to discuss the analysis and interpretation of data in order to enhance trustworthiness and credibility.

7.3 Results

Thirty-four interviews were conducted, including 19 individuals with SCI and 15 family caregivers (8 spouses/partners, 7 parents). Among the 34 participants, 26 individuals were in dyads (13 caregiver-care recipient dyads in total), and 8 individuals participated on their own (2 caregivers, 6 care recipients). All participants discussed changes to their relationships and were included in the analyses. Characteristics of the individuals with SCI and family caregivers are
reported in Table 7.2. While most (75%) of the family caregivers had been providing support for more than 10 years, the remaining (25%) had assumed the caregiving role for only 6 months to 2 years. Care recipients and caregivers had regular contact (26 lived together, and 8 saw each other at least weekly). One care recipient had frequent contact with her caregiver (i.e., lived together) until their recent divorce. Interviews lasted between 45 minutes to 2 hours. To secure anonymity, quotations representing the various themes include only the participants’ group (i.e., care recipient or caregiver).

Individuals with SCI and family caregivers spoke in-depth and openly about their experiences and challenges post-injury, with two emerging themes: 1) deterioration of relationship- this reflects the challenges experienced/factors that contributed to disintegration in a relationship post-injury; and 2) re-building/maintaining the relationship- this reflects the strategies used by dyads to adjust to the changes within the relationship brought upon by the injury. The manner in which caregivers and care recipients interact and cope post-injury is presented as a dyadic coping spectrum in Figure 7.1.

7.3.1 Deterioration of Relationship

7.3.1.1 Difficulty Adapting

Both the individuals with SCI and their family caregivers reported difficulty adapting to the injury post-discharge, and this caused several negative effects, emotionally and physically, within the relationships. Some participants stated that rather than positively coping and creating a new life with the injury as a dyadic unit, they were focused on a rapid recovery. One recently divorced care recipient explained how not being able to adapt to the new life post-injury, coupled with a break-down in communication with her husband led to the dissolution of her marriage:
“I think we really didn't adjust to it, we just kind of went around it. We just kind of tried to do everything we did before. I got injured, and tried to avoid the subject as much as possible, it felt like. We never ... there was always that big elephant in the room, but nobody really wanted to talk about it because nobody wanted … I didn’t want my feelings to get hurt, and I didn’t want his feelings to get hurt. It was always, you almost never wanted to accept that you were going to be in ... even ten years later, you’re still like, well, no ... 15 years later, no, no, I’m still going to walk, that magic pill is going to be available. It was just never accepted that I would be in the chair for the rest of my life, so it was almost like, never addressed.” (CR 7, wife)

Some participants went on to add that due to not being able to emotionally cope with living with the injury, they faced difficulty in physically adapting to the injury as well, such as finding new ways to be physically and socially active as a dyad.

7.3.1.2 Protective Behaviours

When family members were involved in the caregiving process, they often engaged in protective behaviours, whereby they safeguarded the other individual’s emotional or physical wellbeing. This sometimes resulted in detrimental effects on the individual (i.e., care recipient or caregiver) and within the relationship. Several participants described their experiences of using protective buffering within their caregiving relationships. Participants reported hiding worries and concerns and yielding to the other person in an effort to reduce the other person’s upset and burden. For example, in order to protect her husband (caregiver) and their marriage, one care recipient mentioned how she set aside her own hardships and attempted to make her physical pain less discernible and less burdensome on her caregiver:
“I made it look like, you know what, I’m totally okay, don’t worry about me, everything is fine. I almost never wanted to complain about anything to him [caregiver], thinking, oh my god, this is too much already, and if I even tell him that, oh my god, my hands hurt today or something, and I can’t do something, I’m just putting more pressure on a person. I usually would never...I would just kind of deal with the pain, and move on because I didn’t want to put any more burden on that person...I think he got frustrated with me a lot, not telling him what was wrong or something. I think there was a lot of frustration on his part, on knowing what to do or how to help because I wasn’t co-operating, and letting him know what kind of help I needed.” (CR 1, wife)

Similarly, caregivers mentioned they would occasionally hide their distress from their family members who are injured in order to protect their feelings of guilt for requiring daily assistance.

Care recipients also reported that caregivers were sometimes over-protective. Several added that caregivers usually developed a vigilant attitude or some even underestimated the care recipients’ abilities, thus assuming responsibility for all daily tasks. Some care recipients went on to mention that this protective behaviour diminished their feelings of self-efficacy and autonomy, and this, in turn, often led to resentment within the relationship.

7.3.1.3 Asymmetrical Dependency

Although the majority of individuals with SCI reported they required at least some assistance from their family caregivers, there were several participants who relied heavily on their caregivers to meet their physical needs. Some participants mentioned that this asymmetrical dependency within their relationships had resulted in either or both care recipient and caregiver
losing their identities and freedom. Some care recipients had a general expectation of their caregivers to meet all their daily needs, and this resulted in caregivers, who are living under the burden of these expectations, to exhibit signs of frustration and withdrawal. One distressed caregiver explained the high level of physical dependency shown by her husband on her psychological wellbeing:

“He [care recipient] wants to occupy [exploit] me. He wants to occupy me, and what he can do himself, he wants me to do it, yeah. But after, in 2006, I [became] exhausted. I told him that I will not be with him, and then I went back [to parents’] home.” (CG 10, wife)

On the other hand, some caregivers were not able to be flexible, and provided constant round-the-clock care to the injured individuals (i.e., dysfunctional helping behaviour). Caregivers’ protective and caring behaviours developed into more dependency-inducing behaviours (i.e., where caregiver does for the care recipient what he/she should be doing for him/herself), and this contributed to a co-dependent relationship. Examples of dependency-inducing behaviours include completely undertaking basic self-care and instrumental tasks for injured individuals in situations where they are capable of acting independently (e.g., dressing, preparing meals, cleaning, etc.). This behaviour was more prominent in parent-child dyads, particularly as the participants reported it stemmed from a sense of obligation or duty to provide care as a parent:

“When you’re in a wheelchair, people will do everything for you, if you let them. Some people who are injured are more than happy to take advantage of that. Especially parents. I’ve noticed this over the years. It’s really hard for a parent to see their child in that situation. Anybody who sees their loved one struggling, they have a really hard time...
with that and they want to help them out as much as possible, which means they want to do things for them...We’re so focused on the injured individual that we don’t realize what the caregivers are going through. Again, they’re questioning, am I pushing too hard? Should I back off? He’s frustrated, should I take over or should I let him work through that? All of that creates all kinds of anxiety and that anxiety day over day over day really starts to wear on a person. By the time the person, the caregiver, realizes it, their relationship with that individual is probably affected in a negative way.” (CR 14, son)

Several participants noted that not only was this type of behaviour creating an asymmetrical dependency within the relationship, but also reduced the care recipient’s self-efficacy and autonomy.

7.3.1.4 Loss of Sex and Intimacy

Several participants in romantic relationships mentioned they experienced loss of sex and intimacy post-injury. Role change from spouse to caregivers was reported by dyads as a key factor in changing the dynamics of the relationship and caused a strain in the couples’ relationships. Several participants added that due to the psychological distress associated with providing care, particularly, the constant care provision for individuals with tetraplegia, they could not connect intimately with the care recipients. As one care recipient put it: “As much as she gives me care she is more upset, so it’s more difficult and bonding is more loose (CR 10, husband).” Some individuals described initial apprehension and concerns about initiating sexual intimacy with their partners. Other participants reported that a loss of spontaneity within their relationships interfered with their ability to bond and build intimacy. Individuals felt the constant routine associated with providing care left no room for creativity in their romantic relationships.
One care recipient explained how lack of spontaneity resulted in her and her caregiving spouse’s recent divorce:

“\emph{I think you just get into a cycle, very repetitive, you just kind of get used to the way things are done, and then you just repeat them every single day, so it’s just kind of forgotten. I think that’s a lot what broke us apart, it was just, he started doing his own stuff, that I wasn’t able to do, and I was left alone a lot. I thought, well, why bother staying...Again, there was no being spontaneous if you felt in the mood or whatever, it was very calculated, okay, well, it’s going to happen. I guess I could not be spontaneous, so everything was mapped out. That it’s almost like, I don’t know even if it’s worth it anymore. It’s just like, same thing over and over, there is no variations to it, I’m going to say.}” (CR 7, wife)

7.3.2 Re-Building/Maintaining the Relationship

7.3.2.1 Interdependence

Although the individuals with SCI felt they were more dependent on their caregivers for assistance with daily activities, both participant groups emphasized the need to follow an interdependent approach to managing their relationships. Participants described interdependence as both individuals within the dyad being mutually reliant on each other (i.e., having equality and balance in how each individual’s needs are met), while being able to maintain their autonomous identities. Both participant groups noted that they needed to address their needs and concerns to understand their roles within the caregiving relationship. For example, most individuals mentioned the need for open communication in caregiving situations whereby the caregiver needed to address caregiving boundaries (i.e., caregiving tasks he/she is willing to and capable of
doing) and the care recipient needed to direct care (i.e., how and to what level he/she wants assistance with ADLs). As one care recipient had suggested:

“You have to allow your caregivers to have an out. Some days they just don’t feel like doing it and other times they don’t want to do what you need done. Some caregivers would be okay with helping you with catheterization and wound care, but bowel care, no thank you, they don’t want anything to do with that. Whereas, another person would be the exact opposite. They have to be honest and up front about where their limits are. That’s something that should be established right at the very beginning...You’ve got to remember, the caregiver is probably somebody very close to the person who’s injured, so they’re going through all that emotion and that sense of loss, how is this going to affect their lives, all that. They’re going through all of that as well. The emotional burden on your caregiver when you’re first injured can be psychological, can be physical, can be a lot of different ways, and that leads to caregiver burnout, that leads to deteriorated relationships and all kinds of other problems. So, right in the beginning, have that discussion. Communication with your caregiver is so important. If they don’t have the communication skills, if their relationship is lacking in any way, this is going to show it. Add the burden of the injury and the caregiving and it’s really hard for a lot of couples to manage that situation.” (CR 13, husband)

Although the issue of directing care and setting boundaries was brought up in parent-child relationships as well, a determined commitment to remain in marriages by having such open communication was mostly expressed by spouses. Where physical assistance was required, several individuals were able to share household tasks, dividing them based on what the individual with SCI wanted and was able to do: “I do a little bit of laundry, like I put the stuff in
the washer and transfer it to the dryer, but she folds the clothes because I really hate folding clothes. If she has a faucet leak, then I’ll fix that, so there’s stuff like that. So, we trade back and forth that way.” (CR 9, husband)

It was also noted by both care recipients and caregivers that just as it is important to be mutually supportive in a caregiving situation, it is also necessary to maintain autonomy. Participants explained that by maintaining autonomy, they were able to pursue their own interests and passions. One caregiver described the successful interdependent interaction between himself and his injured wife whereby they followed their own interests while also coming together to participate in dyadic activities:

“...or down in the country, she can just do that by herself and see her friends and meet deadlines, and I can go and play tennis at the club etcetera. Although we do in the summer, we spend about three or four days in the country and less in the city...She found a place which has adapted safari vehicle, so away we go...We’re together but not necessarily that overpowering in any way, not too dependent on the other. It’s just a matter of we’re here for each other. This is perhaps blowing one’s own horn, but we’ve hardly, if ever, had arguments. That’s almost the earmark of our marriage.” (CG 6, husband)

Some caregivers further added that in order to ensure an interdependent relationship, they had to learn when to step back from caregiving tasks, as well as have open communication with their injured family member. Furthermore, numerous participants, both caregivers and care recipients, emphasized the need for more relationship-based education, including communication techniques and skills that are necessary to establish an interdependent caregiving relationship.
7.3.2.2 Shifting Commonalities

Both care recipients and caregivers had noted that due to the changes in psychosocial functioning post-injury, considerable adaptation was necessary as a dyad to re-build their relationships. Several participants reported that they shifted commonalities whereby the dyads changed focus of pre-injury common interests to adapt to the new life post-injury (i.e., discontinued pre-injury activities and focused on new activities to do as a dyad post-injury). The majority of individuals enhanced intimacy through a change of focus on shared activities, rather than focusing on the loss of sex: “I think you just have to re-shift it to commonalities of things that you enjoy to do together, such as watching movies, and baseball. Re-shifting to commonalities in other areas” (CG 9, wife). Several caregivers had added that they had shifted commonalities based on the care recipients’ abilities and interests:

“He loves music, he plays the guitar really well. And that’s sometimes what I do too, when he comes to my place. He has his guitar here, so I’ll get it out and say how about singing me some music? And he’ll say, okay. And sometimes he writes songs and whatnot too, and I sit and I listen to them and the whole bit, so it’s things like that.” (CG 13, wife)

Shifting commonalities ensured that individuals with SCI did not feel rejected or isolated, and allowed the dyads, particularly spouses, to increase their opportunities for intimacy.

7.3.2.3 Adding Creativity into Daily Routine

Using creativity in caregiving activities was often reported by caregivers. However, a few participants (spouses) reported that it was necessary to incorporate imaginative strategies in daily caregiving tasks, not only to effectively complete care-related tasks, but also to engage with the care recipient intimately. Adding creativity into daily routine helped spouses to rekindle romance
in marriages. One specific strategy used in spousal relationships was incorporating role play in day-to-day activities:

“One of the things you develop with your partner is you like to role play. One of the common role plays is nurse-patient, for example. That’s how you could incorporate your disability into your sex life. I’m just trying to give an example of how you can incorporate some of the caregiving into a more intimate act... At the same time, she’s caregiving, but it kind of changes to more of a romantic experience. I’m not saying this works for everybody, I’m just saying, keep an open mind, because by doing that you’re reducing the caregiving aspect of it and it’s more of a different way of being intimate... The way I’m talking to you, the ideas that I’m talking about now, about using caregiving in intimacy, that was not talked about in rehab at all. This is stuff that I’ve learned through the years. I think in the beginning, something like that, just giving a couple that idea that your caregiving doesn’t necessarily mean that it’s a medical environment. It might take like a year before you can get into this kind of thinking, like this isn’t probably something you’d do the first time, but just to have it out there that this is a way we can lessen the caregiving role and add to the more intimacy.” (CR 16, husband)

7.3.2.4 Creating a New Normal

Creating a “new normal” was described as progressively establishing a new routine as a dyad with a focus on the individual with SCI’s abilities. Both care recipients and caregivers noted that life does not return to their former routines post-injury. Therefore, they had to create a new normal, such as developing a new daily routine whereby the injured individuals contributed to household responsibilities according to their level of function. For example, several care recipients who were originally the primary earners prior to the injury had returned to work, but
as part-time and/or with new jobs accommodating their capabilities so as to reduce the financial strain on the caregivers. As one parent caregiver proudly stated:

“...he says, mom, I am not going to be on this the rest of my life. I can work. Yes, even if I’m in a wheelchair the rest of my life, I am not going to be on government assistance for the rest of my life. If I have to do a desk job, which was not his ideal job...like I say, he wanted to be a police officer and be out doing things. But if that doesn’t work out, he said I’m going to have a job.” (CG 19, mother)

Several participants also acknowledged that undertaking household chores (e.g., cooking, laundry, etc.) and other daily activities (e.g., providing care to young children) that were not their former roles allowed them to create a new normal as a family. One caregiver described how although his injured wife is not physically able to participate in leisure activities as before, they were able to reach a new normal as well as redefine their relationship by discovering alternative ways to be socially active as a couple:

“...we carried on accordingly. I mean we had to, of course, learn a lot of new aspects in terms of making life acceptable and comfortable as much as possible. So, I think we did kind of a dip in the graph, but we pulled ourselves up again to a level of normality. Of course, it would have been so much easier for [care recipient] to be in good health and we would have done what many of our friends do. But we do it still, in brackets. They travel all over the world. So, do we, except we always have to put the caveat in, well, is it adapted, what are the possibilities of doing a, b, and c. Which when people, for example, go on a cruise, they can book an excursion to Machu Picchu or something, we can’t. Things like that. Those are little things which curtail our mobility, but nevertheless we’re doing it anyway and we look forward to that. I think that allows both of us to not miss out
shall we say. It would have to be recalibrated and adapted, but we’re doing it anyway.

And that I think is something that is very bonding and very uplifting for both of us.” (CG 6, husband)

Both participant groups further reported that a dual effort was necessary as a dyad in working together towards realistic recovery expectations, utilizing effective communication skills.

7.4 Discussion

The current study aimed to understand the factors that may challenge the stability of relationships post-injury, and strategies used by care recipients and caregivers in maintaining/re-building their relationships. The factors that challenged relationship stability include: protective behaviours, asymmetrical dependency, loss of sex and intimacy, and difficulty adapting. The strategies used by care recipients and caregivers to maintain/re-build their relationships include: interdependence, shifting commonalities, adding creativity into routine, and creating a new normal. To the best of our knowledge, this is one of the few studies to provide insight into the impact of SCI on parent-child caregiving relationships (discussed below). In addition, the majority of studies have focused on the negative impact of SCI on relationships (Chan, Lee & Lieh-Mak, 2000; DeSanto-Madeya, 2009; Kreuter et al., 1998); this is the first study within the SCI population to identify various dyadic coping strategies used by care recipients and caregivers to maintain/re-build their relationships. Indeed, the manner in which caregivers and care recipients interact and cope post-injury can be visualized across a spectrum. Figure 7.1 presents a dyadic coping spectrum consisting of the identified challenges experienced/factors that challenge relationship stability and corresponding strategies that care recipients and
caregivers used in negotiating these challenges/changes within their relationships post-injury. These are discussed below in the context of the existing literature.

Studies have frequently documented that individuals with SCI, particularly those who are tetraplegic, rely on their family members for support with daily activities (Rabeh & Caliri, 2010; Blanes, 2005). As such, the present findings extend those of previous authors in that our participants did acknowledge a presence of asymmetrical dependency within their relationships. Our study corroborated DeSanto-Madeya’s (2006) finding that such asymmetrical dependency created a sense of loss for individuals with SCI and their family caregivers. Our findings further indicate that caregivers who were burdened by over-dependency by their injured family member portrayed signs of frustration and withdrawal, which led to emotional detachment and reduced likelihood of intimacy. This was also noted by Milligan and Neufeldt (1998) who described that an individual with SCI who aims to minimize the impact of his/her injury on the caregiving partner would make a more “attractive candidate” for a long-term relationship compared to an individual who excessively relies on his/her partner.

In addition, the current study further highlighted the detrimental effects within relationships due to co-dependent behaviours exhibited by caregiver-care recipient dyads. A mutually-fed escalation occurred between dyads whereby caregivers’ protective attitudes (due to underestimating injured individual’s functional ability, or concerns for safety) resulted in dependency-inducing behaviours that may have contributed to care recipients being more dependent. This spiral causes the dyad’s interactions to become rigid, and often led to resentment within the caregiving relationship. Interestingly, this co-dependent behaviour identified in our study can be explained by Blalock’s (1985) nonrecursive model of caregiving and dependency. The model explains that dependency-inducing behaviours by informal caregivers are a function
of care recipient dependency needs. Indeed, care recipient dependency needs activate the cycle that can lead to more dependency-inducing behaviours by caregivers who begin to “do for” care recipients (Blalock, 1985). This, consequently, may reinforce dependent behaviours by care recipients, and a cycle of care recipient helplessness followed by caregiver strain may be prompted. Our findings further indicate that such dependency-inducing behaviours are more prevalent in parent-child caregiving relationships. Although the participants in our study had stated this behaviour was due to a sense of obligation as a parent to provide assistance to their injured child, Young (2007) further attributed feelings of helplessness and guilt as factors of parents usually continuing dependency-inducing behaviours. Moreover, while several individuals expressed profound distress within their relationships, some talked of how they had adjusted to the changes and had followed an interdependent approach to re-building their relationships. Consistent with our findings, another study by Chan (2000) also found that sharing household responsibilities based on what the individual with SCI is capable of doing (i.e., if upper limb function was not affected) is a key strategy used in strengthening mutual respect and intimacy. In order to reduce dependency-inducing behaviours and encourage an interdependent caregiving relationship, family caregivers must learn when to step back from caregiving tasks, a skill crucial in ensuring sustainable caregiving (as mentioned in chapter 6).

The participants in our study reported that constant care provision brought about psychological distress among caregivers, leading to caregivers not being able to intimately connect with their injured spouse. Particularly, the obligation to fulfill such caregiving duties and responsibilities on a daily basis was associated with the role change from spouse/partner to caregiver, and directly affected the loss of sex and intimacy in couples. A similar theme of “post-injury shift in relationship dynamics” (i.e., re-defining the spousal role) was determined by
Dickson and colleagues (2010) in their study focusing on the impact of assuming the primary caregiver role following traumatic spinal cord injury. The authors in that study identified that performing bodily tasks for the individuals with SCI (e.g., cleaning the individual after an ‘accident’ or emptying the colostomy bags), resulted in loss of sexual relationship. Consequently, this loss of sexual relationship reduced the former spousal or lover role so that all that was left was the duty to perform practical tasks for their injured spouse, and to undertake a more “motherly/fatherly” role (Dickson et al., 2010). Speziale (1997) further reported that even slight adjustments in sexual intimacy can reduce the chance of maintaining ‘closeness’ and can result in strain within the spousal relationship. The similarities between our findings and other studies lead towards the question: if certain types of care activities (e.g., performing bodily tasks) reduce intimacy within relationships, should family caregivers assume responsibility for such tasks? The responsibility for ensuring that the health care needs of the individuals with SCI are met should not rest solely with family caregivers. Expanding the role of formal caregivers (e.g., personal support attendants) in performing certain care activities, such as bowel care (which hired caregivers are often unwilling or unable to perform [Charlfue et al., 2016]) may be a possible avenue to ensure sustainable intimate relationships.

Despite this, several of our participants did report that they were able to positively re-appraise the situation by utilizing innovative coping strategies within their caregiving relationships. Although developing a routine to manage caregiving tasks has been noted as an important skill to ensure competent caregiving (as mentioned in chapter 6), it also often leaves little room for creativity or spontaneity in romantic relationships. Indeed, Dickson and colleagues (2010) reported that a lack of spontaneity can be detrimental to the family caregiver’s self-esteem (feelings of entrapment and invisibility)- perhaps a likely cause of difficulty in bonding.
with the care recipient. Role play, as a strategy to add creativity into routine caregiving tasks, was mentioned in the current study to cope with the loss of sexual relationship and shift in dynamics of the relationship. The participants in this study mentioned that this ‘trade-off’ of role interaction (using intimacy in caregiving) diminishes the perception of the ‘caregiver role’ and enhances the ‘spousal or lover role’. Role play or intimacy in caregiving is not a well researched topic; nonetheless, this is an important aspect in caregiving that must be further explored in order to support couples adjusting to their romantic relationships post-injury.

A study by Kreuter and colleagues (1998), that explored partner relationships, functioning, mood and global quality of life of individuals with SCI, identified several reasons for divorce. The reasons included difficulties adapting to new physical functions, challenges in maintaining the relationship, and/or unwillingness to live with the injured individual (Kreuter et al., 1998). Our results further suggest that a dyad’s anticipation of the injured individual’s quick recovery during the early stage and hoping that the situation is temporary had led to maladaptive behaviours within their relationship. Wiles and colleagues (2002), in their qualitative study on patients’ and carers’ expectations of recovery following stroke, identified that expectations of complete recovery may be a coping mechanism for patients and caregivers, which demonstrates a psychological need for optimism and hope. Although this may be true, our findings indicate that unrealistic recovery expectations by both individuals with SCI and their family caregivers resulted in the dyads not being able to cope with the new life post-injury, and losing sense of control over their future after realization of the permanent nature of the injury. This led to resentment and withdrawal in dyads, and consequently disintegration of relationships. Furthermore, unlike stroke, the functionality of the injured individual does not improve over time (Dickson et al., 2010), and the possible permanency of the injury (Sekhon & Fehlings, 2001).
requires a dual effort by both individuals with SCI and their family caregivers in accepting or finding approaches to adapting to the new life post-injury.

Angel and Buss (2011) suggested retaining some elements from the previous life as a possible strategy to adapting to the injury for individuals with SCI and their caregiving partners. Conversely, our findings suggest creating a new normal by gradually establishing a new routine as a dyad as another approach to adapting to the new life post-injury. The theme ‘creating a new normal’ is consistent with Strauss and colleagues’ (1984) description of normalizing as a fundamental strategy among individuals with chronic diseases and illnesses. Feeling normal and attempts to normalize are vital concepts to individuals with SCI (Dewis, 1989), and families continuously change their perceptions of ‘normal’ contingent on the injury and family situation (Deatrick, Knafl & Murphy-Moore, 1999). Indeed, the participants in the current study strived to create a new normal by identifying alternative ways for the injured individuals to be active in day-to-day life based on their level of function, and that is beneficial to the dyad and family as a unit (e.g., shifting from being the breadwinner to a domestic role). Chan’s (2000) findings corroborated our study in that paraplegic men changed their role from being the primary earner in the family to taking on more household chores and providing care to children. The similarities between our findings and other studies indicate that creating a new normal requires care recipients and caregivers to simultaneously shift former social roles and norms, an aspect that has rarely been explored within caregiving literature in SCI.

7.4.1 Limitations

Despite the strengths of the current study, a few possible limitations apply. With regard to the recruitment of participants, it is possible that a selection bias may have occurred. It is likely that those participants who agreed to participate may have been better adjusted to injury than
those individuals who declined participation. Also, the majority of family caregivers in the current study were females. This is not uncommon considering the fact that in Canada, SCI predominantly occurs in males (Noonan et al., 2012); however, future research should be directed towards exploring the experiences of male caregivers and its impact on relationship dynamics and marital adjustments.

7.4.2 Implications for Practice and Service Provision

Evidence-based interventions are needed to help individuals with SCI and their family caregivers adjust to the many personal and interpersonal challenges experienced post-injury. Findings from this study revealed the need for relationship-based education; particularly, communication skills training, to help dyads living with SCI to manage challenges, negotiate changes, and facilitate positive interactions within their relationships. Communication styles that previously worked in relationships may not be successful post-injury. Furthermore, counseling during rehabilitation could educate and prepare individuals with SCI and family caregivers for the challenges that may arise in daily life post-discharge into community. Chan (2000) noted the importance of considering the dyad as a single unit to promote increased understanding and preparedness post-injury. The possible value of formal support from healthcare professionals to help care recipients and caregivers to negotiate improvements in communication within their relationship could potentially reduce long-term issues, including irreparable damages in the nature of their relationship. In combination with professional support, connecting family caregivers with peer support groups (i.e., matched peer mentor and mentee) could also help prepare them for their caregiving role, as well as reduce feelings of loneliness and social isolation and psychological distress (Sheija & Manigandan, 2005). It is important to also recognize that timing of emotional or psychological support is vital to developing a system that
is responsive to caregivers’ ‘readiness’ to receive such specific support (Cameron & Gignac, 2008). Although readiness to receive emotional or psychological support is dependent on the individual’s adjustment process (Arango-Lasprilla et al., 2010), the findings from the current study suggest the possible value of offering counseling and peer support prior to discharge from inpatient rehabilitation or early in the transition to the community. This ensures relevant support for individuals with SCI and families to help them maintain the stability of relationships post-discharge (i.e., during the first year post-discharge), a time period where most family dissolution and divorce occurs (Conti et al., 2016).

**7.4.3 Conclusion**

Overall, this study demonstrated that individuals with SCI and their caregiving partners experience a range of emotional, psychological, and relationship challenges post-injury. However, collaborating as a dyadic unit, care recipients and caregivers could negotiate these challenges and changes within their relationships brought upon by the injury by devising adaptive strategies to sustain their relationships. These findings should further alert healthcare professionals (and/or peer support groups) as to the need for possible education and training (e.g., communication skills training, coping strategies) as well as counseling to prepare dyads to negotiate changes within their relationships post-discharge. This study is an important first step in advancing exploratory research about the factors that challenge the stability of relationships as well as various dyadic adaptation and interaction strategies used by individuals with SCI and their family caregivers in fostering healthy caregiving relationships.
Table 7.1: Examples of Open-Ended Questions from the Interview Guides for Impact of SCI on Relationships

1. Caregiver: Do you feel that your relationship with your partner/child changed after his/her injury?
2. Caregiver: How did you and your family member handle sex and intimacy during the early stage of injury and have there been any changes now (please explain)?
3. Caregiver: How does providing care to your family member impact your other roles as a mother/father, spouse, active community member, etc.?
4. Care recipient: Can you please tell me how you and your family member adjusted to the changes after discharge (i.e., immediately after discharge and/or past the 10 years)?
5. Care recipient: From your perspective, what do you think are some benefits of your family member being the primary caregiver?
6. Care recipient: How do you think providing care to you affects your family member emotionally (positively and negatively)?
   a. Probing: How do you help your family member cope with these negative emotions when providing care to you?
Table 7.2: Characteristics of Participants in the Study

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<td>Rebuilding/Maintaining Relationship</td>
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Figure 7.1: Caregiver-Care Recipient Interaction/Behaviour Spectrum: Identified Factors of Deterioration of Relationship and Associated Strategies in Rebuilding/Maintaining Relationship
Chapter 8
Discussion

8.1 Overview

The aim of this thesis was to understand the caregiving experiences and support needs of family caregivers of individuals with SCI. While results from this research were presented in four distinct chapters, findings were interconnected. In this chapter, I will begin by describing the synthesis of the key findings, by discussing SCI caregiver support needs in the context of the literature, as well as in the context of current policies and practices. Subsequently, I will outline the key recommendations to meet the support needs of caregivers. Following from this context, I will discuss the strengths and limitations of the study, suggestions for future research in SCI caregiving and supportive care, and knowledge translation and policy implications of this research.

8.2 Synthesis of Findings: SCI Caregiver Support Needs

The key findings from each of the individual papers (chapters four to seven) combine to provide a comprehensive picture of the support needs of family caregivers of individuals with SCI. Specifically, the factors related to the need for additional care recipient supports (based on impairment-related and sociodemographic factors), facilitators and barriers experienced in providing care, skills required to enhance competent caregiving, as well as factors that may challenge the stability of relationships post-injury prompted in-depth analysis into the kind of support family caregivers of individuals with SCI need. As mentioned in the literature review, for family caregiving to be sustained, the outcome of the caregiving role needs to be positive for both the caregiver (e.g., reduced adverse effects of caregiving or burden, enhanced health and
well-being) and care recipient (e.g., optimized care) (Baker et al., 2017; Revenson et al., 2016). Keeping this in mind, the identified caregiver support needs considered both caregiver and care recipient-related factors (i.e., care recipient-related factors that translate to caregiver support needs). Caregiver-related factors include physical and mental health, age, availability (family obligations, employment status), competency (caregiving experience, formal education/training, medical knowledge and skills), family dynamics (strength of relationship with care recipient), financial situation, and willingness to provide care. Care recipient-related factors include physical and mental health (injury-related, general health and wellbeing), age, and level of independence (how and to what level care recipient wants assistance). Throughout the chapter, caregiver and care recipient-related factors contributing to caregiver support needs will be discussed. In the current study, support needs are defined as various types of assistance- based on caregiver and care recipient-related factors- required by family caregivers of individuals with SCI to ensure sustained caregiving.

The subsequent sections discuss the various support needs of family caregivers of individuals with SCI including: personal attendant support, home care professional/medical support, respite, psychosocial support, and information/training (Figure 8.1).
8.2.1 Personal attendant support

Individuals with SCI required ongoing support with self-care activities (e.g., bathing, dressing, transferring, bowel and bladder care) as well as iADLs (e.g., preparing meals, housekeeping, transportation/driving) over their lifetime. The practical assistance needed by individuals with SCI indicates the crucial role family members play in meeting the caregiving needs. This was particularly true for individuals who are older, with a higher level of injury (i.e., tetraplegia). As in our study, other studies have reported that individuals requiring more assistance with ADLs are significantly older and had lived longer with a SCI (Liem et al., 2004; Dickson et al., 2010). Furthermore, function among individuals with SCI does not improve over time.
time, and this may result in unique challenges brought about by the combined effects of aging and injury (Schulz et al., 2009), and therefore, require increasing support from caregivers. Although older caregivers, with more caregiving experience, may have better adjusted to the caregiving role and learned to balance their responsibilities with other parts of their lives (Arango-Lasprilla et al., 2010), they may have developed their own health problems and functional or mobility limitations that make it more difficult or infeasible to provide care to their injured relative (Thompson, 1999). In addition, higher neurological level of injury, as in the case of individuals with tetraplegia, may require more demanding roles of family caregivers, and may require caregivers to provide a higher level of assistance in ADLs and more time spent in providing care (Dreer et al., 2007; Rabeh & Caliri, 2010; Blanes, 2005). Estimates of the hours of care provided by family caregivers vary, with some reports ranging from as low as 1 hour per day to as high as 24 hours per day (mean care hours per day ranged from 2 hours to 12 hours) (Smith et al., 2016). Our study further demonstrated that family caregivers of individuals with tetraplegia also spent a substantial amount of time performing care tasks, both throughout the day with assistance with ADLs, and during the night with tasks such as repositioning/turning in bed and intermittent catheterization. Indeed, time spent caregiving on a daily basis is dependent on the level of injury and age of the individuals with SCI, and this evidently can substantially increase caregiver needs.

As such, older individuals with complex SCI (e.g., tetraplegia, non-healing wounds, respiratory compromise) have specific ongoing practical needs that family caregivers alone cannot meet, and thus require external support. Increased access to personal attendant services, such as PSWs, could reduce the work load, and consequent strain, among family caregivers as well as attend to the practical support needs of the care recipients. Other studies reporting the
impact of employing hired caregivers on family caregiver outcomes (Arango-Lasprilla et al., 2010; Chan, Lee & Lieh-Mak, 2000) corroborate our findings in that additional PSW support can provide greater flexibility and contribute to maintenance of work-life balance with additional time to pursue activities in other areas of life. Also, employing PSWs to undertake certain personal care responsibilities, such as bowel care, may improve the chances of maintaining closeness between the individuals with SCI and their family members, and ensure sustainable intimate relationships between couples. In addition, given that family caregivers of individuals with SCI frequently experience insufficient sleep due to providing care throughout both day and night-time hours (LaVela et al., 2015), as well as the ongoing support required by individuals who are older and/or have tetraplegia, the necessity of employing a live-in or night-time PSW becomes increasingly important. Chan, Lee & Lieh-Mak (2000) reported that burden was relatively lower among caregivers who were not the sole person responsible for the care of the individuals with SCI and employed a hired caregiver. Furthermore, a growing body of national and international evidence suggests that access to PSW support allows care recipients to stay at home safely (a preferred environment) as opposed to more costly institutions (Lum, Sladek & Ying, 2010). This is particularly true for individuals with SCI who are older and had a recent onset of injury who may not have a family caregiver or whose caregiver is not physically capable of providing necessary care. Indeed, the need for PSWs will increase steadily as the individuals with SCI age and live longer with more complex needs.

While additional practical support in the form of utilizing PSWs may lead to several positive caregiver and care recipient outcomes, our study highlighted the added stress and dissatisfaction with hired caregivers indicating a lack of training, substandard quality of care, inconveniences caused due to constant supervision, and high rates of staff turnovers. This can be
explained by several contributing factors, outlined below. First, there is a lack of standardized training and regulation of PSWs (Kelly & Bourgeault, 2015). Unlike most healthcare workers in Ontario, PSWs are not regulated, implying there is no governing body that sets standards for the requisite knowledge and skills needed to provide competent and quality care to the individuals requiring assistance. Furthermore, there is considerable variability in the training of PSWs, resulting in inconsistency and incongruency of skills, knowledge and responsibilities (Health Professions Regulatory Advisory Council [HPRAC], 2006; Keefe & Légaré, 2011; Lilly, 2008; Laupacis & Born, 2012). Second, there is variation in the level of supervision of PSWs. Supervision by regulated healthcare professionals (if available) is usually indirect, occurring through telephone meetings and chart reviews (HPRAC, 2006). As the participants in our study reported, the added task of training, and in some cases, supervising new PSWs resulted in burden among family caregivers. Finally, PSWs are poorly compensated and work is often sporadic (Kelly & Bourgeault, 2015), raising concerns regarding high PSW turn overs. Particularly, being a PSW in the community care sector (which is the case for the majority of PSWs providing assistance to individuals with SCI) in comparison to institutional care settings (i.e., hospitals and long-term care facilities) tends to lead to a higher rate of turnover due to lower pay rates, fewer benefits, less job security, and irregular and inconsistent hours (Lum, Sladek & Ying, 2010). Indeed, turnover rates among PSWs affect the quality of care provided to the individuals with SCI and their families; this leads to fragmented continuity of care (e.g., important health information about individuals with SCI may not be passed along leading to adverse outcomes, and care recipients and families must gain new trust and comfort).
8.2.2 Home Care Professional/Medical Support

Our findings also suggest that individuals with SCI required more support on a daily basis with the management of secondary health conditions. Frequently mentioned secondary health conditions included neurogenic bowel dysfunction (e.g., constipation), neurogenic bladder dysfunction (e.g., detrusor overactivity or incontinence), autonomic dysreflexia (due to bladder overdistension, a blocked or kinked catheter, or constipation), and pressure injury (due to immobility and spasticity). As our participants reported and other studies also demonstrated that family caregivers undertake responsibility in the prevention and management of certain secondary health conditions, such as performing skin checks (Guilcher et al., 2013) and timely repositioning (Houghton, Campbell & CPG, 2013) for pressure injuries, regular medication review, and monitoring of nutritional status for bowel care (Chen & Nussbaum, 2000; Correa & Rotter, 2000; Badiali et al., 1997; Stiens, Bergman & Goetz, 1997). This is particularly true for individuals with tetraplegia versus paraplegia. For example, some individuals with paraplegia may be able to inspect their own skin, whereas individuals with a higher level/complex injury (e.g., tetraplegia) require assistance from a caregiver (Houghton, Campbell & CPG, 2013).

However, individuals with SCI may also experience certain health condition, requiring support from family caregivers to carry out more intricate and complex nursing or medical tasks related to monitoring, assessing, and managing such conditions (e.g., UTI management, pain management, colostomy care, medication administration, special diets, wound care), that were previously provided by formal healthcare professionals (Schulz et al., 2009). It is evident that family caregivers are providing medical care to the care recipients in their homes; however, it is surprising that none of the studies- within the caregiving literature as a whole- raised awareness on whether informal caregivers should be accountable for performing these complex tasks.
unsupervised. Indeed, such care entails a level of knowledge and skills unaccustomed amongst lay individuals (Dickson et al., 2010). In contrast, Elliott, Shewchuk and Richards (1999) reported that the responsibility for adherence to medical regimes and ongoing prescriptions often resides with family caregivers, and nonadherence will lead to higher risk for pressure injury development among individuals with SCI.

While several of these secondary health conditions are responsive to appropriate primary care management (Hitzig et al., 2008), they are key contributors for re-hospitalization and/or death in the post-acute phase (Dryden et al., 2004; Pickelsimer, Shiroma & Wilson, 2010; DeVivo & Chen, 2011). This suggests that support needs in the community are not being met for individuals with SCI and their family caregivers. Given the prevention and management of certain secondary health conditions requires specific clinical knowledge and skills, professional/medical home care services to manage such health conditions could reduce the distress for family caregivers in having to perform complex medical tasks, as well as reduce rehospitalization and improve the health and wellbeing of individuals with SCI. Dryden and colleagues (2004) suggested that primary care physicians may be ideally suited to facilitate ongoing contact with individuals with SCI and their families after discharge into the community as an effort to prevent secondary health conditions. However, our study demonstrated that primary care physicians may not be informed about the specific clinical issues related to SCI (e.g., symptom management). In addition, individuals who are ill are often unwilling to take the time and expense to come for regular evaluations (Canupp et al., 1997), and require professional/medical care in their homes. Home care, which involves licensed regulated healthcare professionals, such as registered nurses (e.g., for medication administration, wound care), physiotherapists (e.g., for coaching of strength and balance exercises to improve functional
performance), dieticians (e.g., for nutrition consultations), provide skilled medical care to individuals with SCI in preventing and managing their secondary health conditions. In many cases, such professional home care services are an essential support to family caregivers looking after individuals with complex needs (i.e., tetraplegic) (Decima, 2002).

8.2.3 Respite

The rising shift of care to the home and community, coupled with a greater complexity in the condition of the care recipients, leads to an increase in the need for respite for family caregivers (Dunbrack, 2003). Our findings suggest that fatigue and physical pain (due to transferring), are recurrent adverse health effects attributable to caregiving, and inhibited family caregivers’ ability to provide optimal care to the individuals with SCI. A study by LaVela and colleagues (2015) further added that a greater proportion of SCI caregivers experienced insufficient sleep and more days without sleep in comparison to caregivers of those with other neurological conditions. The similarities between our findings and other studies indicate that family caregivers require respite care for temporary relief from the caregiving responsibilities in order to improve their own overall health and well-being. In a study by Dickson and colleagues (2010) exploring adjustment and coping in spousal caregivers following a traumatic SCI, they determined that for some caregivers, respite encompassed more of a temporary need to return to their former, pre-SCI normality; while others needed a longer period of ‘time out’ from the home in order to get a proper sense of respite.

Currently within Ontario, the types of respite offered to family caregivers includes: adult day programs, in-home respite, and short stay at long-term care homes. Although caregivers require respite from their caregiving responsibilities, in some cases, they stopped using respite
care services because of limiting factors (e.g., frustrations with the respite services outweighed the benefits (Charlifue et al., 2016)). For example, there are often long delays prior to getting referrals for adult day programs, and many healthcare providers do not have information on how to access this service for the caregivers and care recipients. In addition, the responsibility for transportation to and from the adult day programs resides with family caregivers (Local Health Integration Network [LHIN], 2009). To add, the costs of respite care can also be a limiting factor (Charlifue et al., 2016). In fact, subsidized in-home respite is not available in all areas of Ontario, and families are required to pay a fee for these services. Finally, a key barrier towards accessing respite care (and home care in general) for family caregivers in Ontario involves the assessment of eligibility. The LHIN Home and Community Care provides funded home care (e.g., respite) based on individual care recipient needs (LHIN, 2009). Although focusing on the individual with SCI’s characteristics/needs is certainly important in considering the types of services provided to this individual, it is less pertinent when assessing the support needs of the family caregiver. Indeed, due to the fact that such home care and respite care services are developed to support the caregivers and the care recipients, the needs of the dyad as a whole should be considered (Guilcher et al., 2013). Particularly, considerations of family caregiver characteristics, such as caregiver health (e.g., mentally and physically able to provide care), availability (e.g., family obligations, employment status) and age should be taken into account when determining eligibility for home care and respite services.

8.2.4 Psychosocial Support

The current study draws attention to the broad range of emotional, psychological and relationship challenges experienced by both the family caregivers and individuals with SCI post-injury. Many studies have demonstrated that in the process of caregiving, several psychosocial
issues arise, and this can lead to negative caregiver outcomes. Psychosocial issues such as elevated emotional stress, anxiety, depression, mental weariness, anger, burnout, and isolation have been frequently reported in family caregivers of individuals with SCI (Chan, Lee & Lieh-Mak, 2000; Vagharseyyedin & Molazem, 2013; Post, Bloemen & de Witte, 2005; Arango-Lasprilla et al., 2010; Dreer et al., 2007; Manigandan et al., 2000). As such, the findings from our study also highlight the psychosocial issues (e.g., distress, fatigue, burnout, anxiety, depression) in undertaking caregiving responsibilities, as well as adapting to the new life, particularly for caregivers stepping into the caregiving role (i.e., within the first two years post-SCI). Our findings further demonstrated that a dyad’s anticipation of a quick recovery during the early stage (i.e., unrealistic recovery expectations), dependency-inducing behaviours particularly among parent-child relationships (e.g., not being able to step back from caregiving tasks, feeling guilty for the injured child and obligated to provide care), and challenges in sustaining intimacy in romantic relationships had led to maladaptive behaviours (e.g., resentment, frustration, withdrawal) within their relationships. The challenges in adapting to new physical functions, rebuilding daily life, adapting to the shift in former social/relational roles within relationships, and maintaining the relationship during the early stage of the injury resulted in a higher incidence of divorce and separation within the first 3 years after the injury (Kreuter et al., 1998; Chan, Lee & Lieh-Mak, 2000; DeVivo & Fine, 1985). Indeed, time since injury can have a significant impact on the psychosocial support needs reported by family caregivers (as well as the dyad as a whole), given that adjustment and better coping skills may evolve over time (Arango-Lasprilla et al., 2010). In relating our findings to the existing literature, we can affirm that enhanced access to professional support services (e.g., counseling) as well as community-based social support services (e.g., peer support groups) is required by caregivers of individuals with SCI (particularly prior to discharge or transition to community) since they are involved in
the same way in the psychological process of adaptation to the new life post-injury (Dickson et al., 2011; Boschen, Tonack & Gargaro, 2005). Counseling (both individual and family counseling) can have a significant impact by addressing the needs of caregivers and care recipients (Elliott, Shewchuk & Richards, 2001), and providing tailored strategies to cope with the new caregiving role, maintaining family functioning accordingly (Altman, Cooper, & Cunningham, 1999) and establishing caregiving boundaries. Particularly, intervention research in family health psychology demonstrated that psychoeducational strategies (i.e., combining education and counseling) are more effective than other modalities (e.g., psychotherapy) during rehabilitation, possibly because they address the specific needs of family caregivers (e.g., teaching good stress-management techniques) and frequently involve family members (i.e., family therapy) (Burman & Margolin, 1992; Campbell & Patterson, 1995).

Along with professional support, social support such as peer support groups has been found to be a key for family caregivers of individuals with SCI (Sheija & Manigandan, 2005; Boschen, Tonack & Gargaro, 2005; Conti et al., 2016). Family caregivers of individuals with SCI who had access to peer support groups reported better general health, quality of life, and reduced feelings of loneliness and social isolation and psychological distress in comparison to caregivers who did not have access to peer support groups (Sheija & Manigandan, 2005). Our findings build upon previous studies by delineating the role of peer mentors within the supportive social network in preparing caregivers for their caregiving role. Specifically, the need for support (including informational, appraisal and emotional support) from caregiving peers became of greater importance prior to discharge from inpatient rehabilitation when caregivers required guidance on supporting individuals with SCI in the community. However, our findings further suggest that access to peer support groups is varied based on geography, such that
caregivers living within rural areas experienced barriers to connecting with a peer mentor. Indeed, ignoring the importance of emotional health for family caregivers within the rural region is counterproductive to good rehabilitation practice (Boschen, Tonack & Gargaro, 2005).

8.2.5 Information/Training

In this research, participants indicated that access to information and training opportunities to prepare caregivers for their caregiving role was limited, particularly prior to discharge from inpatient rehabilitation. In fact, comparable results were identified when comparing another similar study conducted among caregivers of community-dwelling individuals with SCI in Ontario, Canada in 2005 (Boschen, Tonack & Gargaro, 2005). The participants in that study reported they had felt unprepared, and this reflected a lack of continuity of services as well as poor timing of information and resources (Boschen, Tonack & Gargaro, 2005). As our participants reported, the participants in Boschen, Tonack and Gargaro’s (2005) study also described the burden of having to learn caregiving tasks through trial-and-error at home. It is surprising that there has been no perceived improvement in the continuity of information/training services over the last decade in Ontario. Indeed, more attention should be given to determining the types of information and training needed by family caregivers of individuals with SCI to reduce trial-and-error learning.

For example, ongoing skills assessment and training for caregivers could be one avenue to reduce trial-and-error learning, and help caregivers feel competent in their caregiving roles. As noted in the literature reviewed at the beginning of the thesis, caregivers often carry out specific caregiving tasks (e.g., intricate medical tasks, practical/self-care tasks, emotional support [Liem et al., 2004; Post, Bloemen & de Witte, 2005]) that entails a level of knowledge and skills unaccustomed among such lay individuals (Dickson et al., 2010). In fact, previous studies have
highlighted that caregivers of individuals with SCI who lack appropriate caregiving skills (e.g., problem-solving skills) are at risk for increased symptoms of anxiety, depression, and poor health during the first year of caregiving (Elliott, Shewchuk & Richards, 2001), and their injured relatives are at risk for developing preventable secondary health conditions (e.g., pressure injuries) during this period (Elliott, Shewchuk & Richards, 1999). In relating our data with existing literature, we can affirm that skills training in the following areas might be particularly useful for SCI caregivers: a) practical skills (e.g., self-care, assessing and managing secondary health conditions); b) logistical skills (e.g., planning/organizing care tasks, administering medication and nutrition, accessing community resources); and c) coping skills (e.g., communicating with care recipient, emotional awareness/self-regulation). It should be noted that although professional healthcare providers should be responsible for the assessment and management of secondary health conditions (e.g., home care professional/medical services, as mentioned in section 8.2.2), the unpredictable and sporadic nature of events related to the onset of certain secondary health conditions (e.g., autonomic dysreflexia) requires SCI caregivers to be competent in recognizing the signs and symptoms, as well as timely management to reduce worsening (or even prevention of life-threatening outcomes) of the condition. An approach to clinical assessment whereby healthcare professionals conduct initial and ongoing assessments to identify each caregiver’s level of skill and target interventions (e.g., skills training program) according to the caregiver’s learning needs is necessary. These skills training interventions may be placed in the inpatient care setting or home upon discharge from inpatient rehabilitation for positive caregiver and care recipient outcomes (e.g., improved health quality of life). Furthermore, considering the longevity of caregiving among the SCI population, ongoing training for family caregivers may also help improve daily function and quality of life of
individuals with SCI and reduce overall caregiver burden as needs change over time (Smith et al., 2016).

In addition to training needs, participants in our study reported that the most prominent barrier to caregiving relates to the challenges experienced in navigating the healthcare and social services system, particularly post-discharge. Discharge from inpatient rehabilitation is a crucial period in the care trajectory for caregivers. Our findings are consistent with previous studies highlighting the elevated anxiety, and concerns experienced due to clinical, logistical and organizational issues during this phase (Marini & Reale, 2010; Lucke et al., 2004; Schulz et al., 2009). Findings from this study indicate that caregivers require information regarding availability and accessibility of community resources (i.e., timely access to reliable information). For example, financial guidance (i.e., informing/directing caregivers to available funding programs) and awareness/access to community resources (e.g., home care, home modifications, and assistive devices/technology) are among the greatest needs of SCI family caregivers prior to discharge from inpatient rehabilitation (Ellenbogen et al., 2006; Arango-Lasprilla et al., 2010). There is a need for an enhanced navigational support service- a centralized point of access (i.e., via a navigator or virtual library) to information, services, and resources in the community for SCI caregivers.

Navigators are trained individuals who assist patients and family caregivers to access available information and services (Ministry of Health and Long-Term Care [MOHLTC], 2009). Although navigation is recognized as a key element of an integrated system of healthcare, it is not yet delivered in a standardized way across Canada. However, Hamilton General Hospital, operated by Hamilton Health Sciences (HHS), was the only Spinal Cord Centre in Ontario to have actively integrated SCI navigators (through SCIO) in their hospital’s acute and
rehabilitation teams (HHS, 2006). Efforts should be increased to develop the SCI navigator role to its full potential and deliver in a more standardized way across Ontario (and Canada). By doing so, this can assist individuals with SCI and family caregivers navigate the system, as well as resolve any health disparities to accessibility of navigators within Ontario.

There are a few virtual platforms in Ontario for the SCI population; however, they mainly focus on the care recipient’s needs and have limited family caregiver-specific information (MOHLTC, 2009). For example, majority of these virtual platforms provide information about living with SCI (e.g., active living and exercise, mental health, nutrition, etc.), or available community services (e.g., attendant care, transportation, supportive housing options, etc.). Although such information is beneficial, there is limited information on family caregiving or resources for family caregivers. Specific examples include, but not limited to: information on assessing and managing secondary health conditions, adjustment after SCI as a family, coping with caregiver burden, aging with SCI, availability of financial resources (e.g., employment insurance compassionate care benefits). A virtual library, a centralized system that can provide online access to a collection of necessary information about caregiver-related issues and support services (MOHLTC, 2009), would be beneficial. Indeed, improving the quality of available information and ensuring caregivers are aware of how to access a full range of services and resources in the community is key to not only ensuring optimized care for individuals with SCI but also reducing distress and anxiety for family caregivers.

8.3 Recommendations Based on Findings

Based on the findings of the support needs of family caregivers of individuals with SCI, including the elements of support (as described above), I propose some recommendations to enhance support for caregivers at the provincial level (please see Table 8.1). Particularly, these
recommendations focus on key actions that could be taken by the Ontario LHINs, rehabilitation hospitals and SCI consumer-based organizations to ensure caregivers’ needs are addressed, thereby promoting sustained caregiving. Some recommendations are specific to SCI and others are relevant to the home care sector as a whole.

Table 8.1: Recommendations to Enhance Support for SCI Family Caregivers in Ontario

<table>
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<tr>
<th>Personal Attendant Support</th>
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<tr>
<td>Support with care recipient self-care tasks and iADLs to reduce workload for family caregivers</td>
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**Recommendations:**

1. Increase funding to home care agencies to provide more subsidized personal attendant services to caregivers of high needs/complex SCI individuals (e.g., tetraplegia, non-healing wounds, respiratory compromise)
2. Increase funding to home care agencies to provide subsidized live-in and night-time personal attendant services to older caregivers at fair market rates to enhance retention
3. Consider both the needs of individuals with SCI and their family caregivers prior to formulating a treatment plan or assigning attendant care resources
   a. Eligibility for personal attendant resources should be identified using a standardized assessment tool (which should also be accessible to the public, so family caregivers can prepare accordingly and create appropriate care plans for injured relatives)
   b. Develop a process for reassessment of home care needs (e.g., personal attendant support) that is case specific (e.g., older individual with tetraplegia, family caregiver with a chronic condition), instead of solely on neurological impairment of individual with SCI
4. Advocate for regulation of personal support workers for optimized client care
   a. Standardize/enhance training and education for PSWs (consistency in PSW training, knowledge and practice)
   b. Include formal training in bowel, bladder and skin care into PSW curriculum (i.e., SCI-specialized training)
   c. Standardize compensation and benefits for PSWs (including travel costs) to enhance retention and reduce PSW turnover
### Home Care Professional/Medical Support

Support with prevention and management of SCI-related secondary health conditions in homes

**Recommendations:**

1. Increase funding to home care agencies to provide more subsidized professional/medical support to family caregivers, particularly for high needs/complex SCI individuals (e.g., tetraplegia, non-healing wounds, respiratory compromise) from licensed professionals (e.g., registered nurses, physiotherapists, dieticians)
2. Enhance the capacity of home care agencies to recruit, train and manage healthcare professionals to prevent and manage secondary health conditions in the community to reduce rehospitalization
3. Consider both the needs of individuals with SCI and their family caregivers prior to assessing home care professional/medical services requirements
   a. Eligibility for home care professional/medical services should be identified using a standardized assessment tool (which should also be accessible to the public)
   b. Develop a process for reassessment of home care needs (e.g., home care professional/medical support) that is case specific (e.g., older individual with non-healing wound), instead of solely on neurological impairment of individual with SCI

### Respite

Provision of temporary relief to family caregivers who are caring for individuals with SCI

**Recommendations:**

a. Develop standardized admission timelines to accelerate referral and admission process to adult day programs
b. Expand services in adult day programs to include services for those who are competent adults with mobility and self-care needs, distinct from those with memory impairment
c. Increase funding to subsidized in-home respite throughout all areas of Ontario
d. Provide minimum entitlement for family caregivers per annum for circumstances where respite would be appropriate/necessary

e. Consider the needs of both the individual with SCI and family caregiver prior to assigning respite care services for caregivers

f. Eligibility for respite services should be identified using a standardized assessment tool (which should also be accessible to the public)

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<tr>
<th>Psychosocial Support</th>
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<tr>
<td>Provision of psychological and social resources (including counseling with licensed professionals and peer support groups) to family caregivers</td>
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<tr>
<th>Recommendations:</th>
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<tr>
<td>1. Recommend counseling (e.g., individual and family counseling) and/or peer support to be introduced during rehabilitation and/or at the transition from rehabilitation to the community period to assist individuals with SCI and family caregivers with adaptation to new life post-injury</td>
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<tr>
<td>2. Enhance capacity of peer support networks in urban and rural regions</td>
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<tr>
<td>a. Increase availability of peer support groups in rural locations</td>
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<tr>
<td>b. Consider matching of peer mentors and mentees by specific characteristics (e.g., age, sex, etiology of injury, time since injury)</td>
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<tr>
<td>c. Establish a range of modalities for peer support programs (e.g., providing telephone or online peer support remotely) for caregivers who have difficulty accessing peer support groups</td>
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<tr>
<td>i. Use the “Virtual Integrated Platform for Spinal Cord Injuries” (VIP4SCI) as a model for peer-to-peer family caregiver mentorship</td>
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<th>Information/Training</th>
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<tr>
<td>Support in accessing information and training opportunities for family caregivers to assist them in their caregiving role</td>
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<th>Recommendations:</th>
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<tr>
<td>1. Recommend the delivery of specific skills training modules (e.g., practical, logistical, coping skills) in inpatient care settings, home upon discharge, or community support centres</td>
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</table>
2. Recommend that healthcare professionals conduct initial and ongoing needs assessment of caregivers that is separate from the needs of individuals with SCI.

3. Develop a virtual library to provide online access to information and resources to support individuals with SCI and family caregivers within the community.
   a. Use the SCI & U (an internet-mediated self-management program for users with SCI [Allin et al., 2018]) as a guide for development of an internet-based support program for family caregivers.

4. Advocate for integration of SCI navigators across the healthcare system to enhance continuity of care for individuals with SCI and family caregivers.
   a. Use the SCI navigator model implemented by HHS as a guideline for expert direction for best practices in implementing other SCI navigator pilot projects across the province (i.e., delivered in a standardized way).

8.4 Strengths and Limitations

8.4.1 Strengths

Collectively, this research has several methodological strengths. This section describes the three major strengths of this study: qualitative method; recruitment strategy; and sample size sufficient to achieve data saturation.

As mentioned earlier, current literature in SCI caregiving consisted mostly of studies that followed quantitative methods (DeSanto-Madeya, 2009; Munce et al., 2014). The qualitative descriptive approach allowed us to gain insights about a phenomenon that has rarely been studied (i.e., SCI family caregiving needs), addressed gaps in our understanding, provided a new perspective on a situation (Schreiber, 2001), as well as contributed to our overall understanding of the lived experiences of family caregivers and care recipients (Creswell et al., 2003). In fact, a major strength of this study is the emphasis on the lived experiences of both caregivers and care recipients and their interplay in understanding family caregiving in SCI. Furthermore, the in-depth study of family caregiving in this population (perceived facilitators and barriers to
caregiving, factors contributing to the need for more support, required skills for competent caregiving, and factors that challenge the stability of relationship post-injury) was particularly useful for producing recommendations for policy making based on the support needs of caregivers (Sandelowski, 2000; Sandelowski, 2010). Indeed, such qualitative research findings are a credible source of research evidence for public health practice (Upshur, 2001; Jack, 2006), including intervention research (Gilgun & Sands, 2012).

Previous research has been limited to the perspectives of the individual with SCI or the family caregiver. However, given the potentially important synergistic effects of caregiving whereby caregivers and care recipients mutually affect each other (Schulz et al., 2009), another strength of this study resides in including both the individuals with SCI and their family caregivers. The use of multiple perspectives, with the majority being in dyads (caregivers and care recipients from the same family), provided the opportunity to compare and contrast their responses, yielding a comprehensive documentation into the kind of support family caregivers of individuals with SCI need in order to ensure sustained caregiving. Indeed, studying the dyad added another layer to the study as it sought to address the extent to which caregivers and care recipients agree as to the types of support the caregiver needs in order to provide optimized care for the individual with SCI. In addition, credibility and trustworthiness was enhanced through triangulation by cross-checking the responses so as to explain more fully the richness and complexity of caregiver-care recipient experiences and support needs.

Another strength resides in the recruitment of family caregivers based on their relationship with the individuals with SCI. The majority of studies have included the spouses of individuals with SCI and did not include other family members, such as parents. Our current study is one of the few studies to provide insight into the impact of SCI on parent-child
caregiving relationships as well as the variability in the level of support provided. In fact, exploring the caregiving experiences between spousal and parental caregivers allowed us to gain an in-depth understanding of the dynamics of relationships as well as the roles and expectations in providing care post-injury.

With respect to the sample size for a qualitative study, several strengths were also noted. Our sample size of 34 participants allowed us to achieve data saturation and conduct a comprehensive analysis of caregiver support needs. For example, a larger sample size allowed for more descriptive detail and ensured a broader variation in caregiver and care recipient experiences (Boschen, Tonack & Gargaro, 2005). In fact, in most of the existing SCI family caregiving studies, sample sizes have been considerably small, with the majority of studies having samples of 10 or fewer participants (Meade et al., 2004). Furthermore, it is believed that this sample size enhanced transferability of the research findings.

8.4.2 Limitations

Despite the strengths of the current study, a few possible limitations apply. These include: 1) limited participants from rural areas (factors such as resource scarcity between regions was not captured in our study); 2) common health conditions (e.g., neurological decline, fracture, peripheral neuropathy, etc.) did not emerge in our study; 3) limited participants from different cultural/ethnic backgrounds (experiences and challenges were not captured in our study); 4) limited participants who were male caregivers; and 5) current study was within a Canadian context, with a large representation from Ontario (may not generalize to other healthcare settings with different health systems). Detailed descriptions of these study limitations have been discussed in chapters four to seven. However, one key limitation with respect to the logistical challenges of conducting research will be highlighted here.
Taking into account the learning curve that occurs within the first two years, as well as the evolving needs required by individuals with SCI over time, purposive sampling by time since discharge (i.e., from at least 3 months to up to 2 years post-discharge, and over 10 years post-discharge from inpatient rehabilitation) was used to select and recruit the participants. However, due to time constraints with data collection as well as potential participants’ willingness to participate in the study, we did not have an equal representation of participants within both time periods. Indeed, the study limitations are linked to bias in the recruitment of participants. It is likely that those who decided to participate in the study may have been better adjusted to the caregiving role than those who declined participation. This is perhaps a possible reason for an over-representation in the over 10 years post-discharge group as they have had more time to adjust to living with SCI and providing care. It should be noted that within one year of injury, is a crucial time for individuals with SCI and their family caregivers, where both explicit and implicit needs arise (Conti et al., 2016). Therefore, we were not able to conduct a comprehensive analysis of the support needs of family caregivers of individuals who have recently been injured.

8.5 Suggestions for Future Research in SCI Family Caregiving and Supportive Care

There are several potential future directions for research that build upon the findings of the current study. In this section, I will highlight key areas for future research in SCI family caregiving and supportive care:

1. Future research on aging and SCI is important as individuals with SCI are just now reaching aging milestones (i.e., 30 or 40 years post-injury), particularly the number of individuals living with chronic injury continues to grow. This could have a significant impact on caregiver support needs as family caregivers may have additional care needs as
both they and their injured relatives age. Further research exploring age and SCI or aging with SCI (i.e., either as both caregiver and care recipient age with SCI, or both individuals being older at onset of injury) may provide additional context into the caregiver support needs in the future. Longitudinal studies could provide valuable information on changes in caregiver support needs over time post SCI as needs early in the care trajectory may differ from those later.

2. Further exploration on the types of support needed by family caregivers of individuals who have recently been injured (i.e., within 2 years post-discharge) is necessary. Particularly, discharge from inpatient rehabilitation is a crucial time for the caregivers of individuals with SCI due to uncertainty in attempting to take on a new role and manage clinical, logistic and organizational issues. Exploration of the support needs, as well as the facilitators and barriers to caregiving experienced by caregivers during the initial stage of transitioning back home is imperative to ensure sustainability of the caregiving role.

3. Although it is evident that mostly women (particularly wives) often assumed the primary caregiver role for individuals with SCI, future research should also be directed towards exploring the experiences of male caregivers in order to increase the relevance of care models and programs for both male and female caregivers. For example, more attention could be placed on understanding the perspectives of male caregivers and the support needs associated with taking of a wife with SCI, as well as its impact on relationship dynamics and marital adjustments. Such knowledge on support needs could be used to develop tailored programs for this cohort (e.g., male peer support group).

4. The participants in the current study primarily consisted of Caucasian working/middle-class caregivers. Future research could also investigate caregiver support needs in other
sociocultural settings/contexts (e.g., in other cultural/ethnic backgrounds where the experiences and definition of caregiving might differ) to validate the study findings and/or adapt the findings to specific contexts. It is important to understand the impact of sociocultural factors (e.g., education, language, social organizations, as well as social/cultural beliefs, practices, and norms relating to assuming caregiving responsibility) on SCI family caregiving so as to ensure that the needs of culturally diverse populations are considered in implementation efforts.

5. The current study demonstrated that access to resources, particularly peer support groups, is varied based on geography, such that caregivers living within rural areas experienced barriers to connecting with a peer mentor. Future research should consider the geographic variation in exploring family caregiver support needs such that factors that facilitate and hinder the caregiving role (e.g., accessibility of community resources, environmental barriers or resource scarcity) might be considerably diverse between regions. Overall, future research should be directed towards determining how the experiences, concerns and support needs of family caregivers living in rural versus urban settings differ. With respect to peer support groups, future research could also determine the level of peer mentorship/support required by SCI family caregivers at different stages of the care recipient’s journey (e.g., during rehabilitation, transition to home, 10 years post-injury) to enhance the level of support, and improve caregiver outcomes (e.g., increased competency/self-efficacy, reduced distress/strain).

6. The current study briefly highlighted issues concerning the quality of care provided by paid caregivers (e.g., PSWs). Additional research is warranted to compare the care received between informal (family and friends) and formal caregivers (PSWs), in relation to standardized metrics for quality, caregiver skill and competency, and corresponding
health outcomes of individuals with SCI. Future research should also be directed towards identifying core areas of practice for paid caregivers (e.g., PSWs) to develop the PSW role to its full potential (e.g., specialized training in SCI care) and enhance the formal care delivery in the home care system.

7. Within the local context, further research is needed on the barriers to accessibility and funding opportunities for home and community care services for families providing care to individuals with SCI in Ontario. This could provide insight into the shortfalls and gaps in home and community care services for this population as well allow for prospective planning of sustainable support services in the community within Ontario. Future research could also explore the variation in practices across the LHINs and their implications for different regions within Canada.

8. Building on the qualitative findings of this study, future research may examine specific intervention/program needs of SCI family caregivers using a survey methodology. Identifying specific support information and training at each stage of the caregiver-care recipient journey (e.g., during rehabilitation, transition to home, 10 years post-injury), using the “Timing it Right” framework (Cameron & Gignac, 2008), should be considered in future research. For example, determining the intervention components (e.g., modules, mode of delivery, timing, organization, program leaders, etc.) for a skills training initiative for caregivers of individuals with SCI, as well as assessment of its impact could be beneficial.

**8.6 Implications for Knowledge Translation**

Collectively, the findings from this research has considerable implications in planning hospital and community-based support programs/services to improve the health outcomes of
both individuals with SCI and family caregivers. Specifically, the findings from our study provide insight into elements of support that, if implemented within the healthcare/social services system, could assist family caregivers in sustaining the caregiving role long term. Furthermore, using the KTA framework, this thesis focused on the phases of 1) knowledge inquiry (i.e., understanding caregiver needs based on the factors related to the need for more support by care recipients, facilitators and barriers experienced in providing care, skills required to enhance competency in caregiving, and factors that may challenge the stability of relationships); 2) knowledge synthesis (i.e., aggregating caregiver and care recipient data to identify elements of support required by caregivers); and 3) creation of knowledge tools and products (e.g., recommendations based on findings to enhance support for caregivers at the provincial level). Other phases of KTA framework (i.e., the action cycle) could be the focus of future research including application of knowledge in healthcare or community settings (e.g., selecting, tailoring and implementing SCI caregiver support interventions, evaluating outcomes, and sustaining knowledge use).

8.7 Policy Implications

Spinal cord injuries lead to considerable economic burden on the individuals with SCI, their families, and the healthcare system due to increased healthcare costs, and higher rates of morbidity and prematurity mortality (Krueger et al., 2013). The total lifetime cost of SCI in Canada was estimated to be $1,782,698 for complete paraplegia and $1,471,930 for incomplete paraplegia, and $3,026,027 for complete tetraplegia and $2,105,811 for incomplete tetraplegia (CAD) (Krueger et al., 2013). Provincially, SCI costs the Ontario government an estimated $1.38 billion per year, with an average of $120,000 CAD per person (2005/2006) in direct costs of rehabilitation (Munce et al., 2013). Also, it is expected that there will be a significant increase in
the incidence of NTSCI over the coming two decades as a result of the aging population across Canada (Farry & Baxter, 2010). The findings from the current study further highlight the changing demographic (older individuals with SCI) and the associated complex needs brought upon by age (e.g., greater number of concurrent medical conditions).

Our findings affirm prior reports that the aging demographic coupled with the rising incidence of NTSCI in Canada will exhaust current system resources (Craven et al., 2013), particularly the concomitant economic burden on the healthcare system (Krueger et al., 2013). Yet, policies and services for family caregivers of individuals with SCI in Canada are lacking. Findings from this research suggest there are opportunities for support programs and services that could be offered to SCI caregivers. Considering the dearth of national and provincial policies related to SCI family caregiving in Canada, there is a case to be made for the development of policies that could serve to facilitate the planning, development and evaluation of specific initiatives for SCI family caregiving in Canada (e.g., funding regulations, accountability strategies, public awareness/education). For example, this thesis suggested key actions that could be taken to enhance support for SCI family caregivers at the provincial level (i.e., Ontario LHINs). Also, current healthcare delivery in Canada is conducted in silos to a great extent, where diagnosis and management of health conditions are usually targeted independently (Craven et al., 2013) which causes repetitiveness and inefficiencies in care processes (Barnett et al. 2012). The findings from the current study suggest an interdisciplinary approach (i.e., multi-system of care which includes, but not limited to, inpatient/outpatient rehabilitation professionals, community nurses, formal caregivers, etc.) to provide optimized care for individuals with SCI, particularly for individuals with multimorbidity and comorbid SCI-related impairments. Indeed, the findings from the current study could serve to facilitate prospective
planning of sustainable support (e.g., allocation of funds to reflect the priorities of individuals with SCI and families, creation of organized interdisciplinary care) for individuals with SCI and family caregivers in Canada.

8.8 End of Thesis Knowledge Translation Plan

An appropriate dissemination plan will be implemented at the end of the thesis. For example, the findings from the current study will be presented at relevant meetings locally (e.g., Toronto Rehabilitation Institute Research Day), nationally (e.g., National Spinal Cord Injury conference), and internationally (e.g., International Spinal Cord Society conference). The results will also be published in peer-reviewed journals so that they are available to key stakeholders (e.g., academics, policy makers and health planners, healthcare and rehabilitation professionals). Considering the participants in this study were recruited through the RHI, TRI-Lyndhurst, and SCIO, key findings will be further disseminated through appropriate modes (e.g., RHI newsletter, SCIO Outspoken magazine) so they are available to individuals with SCI and family caregivers. Lastly, the policy recommendations (section 8.3) outlined in this thesis could be presented to relevant policy makers and health planners in order to facilitate real change in the planning and implementation of support services for family caregivers within the SCI population.

8.9 Conclusion

This study is an important first step in advancing our knowledge about the support needs of family caregivers of individuals with SCI. Overall, the findings from the current study contributed to a greater understanding of family caregiver support needs within the SCI population based on the facilitators and barriers to undertake and sustain the caregiving role in
the community, factors related to the need for more support by care recipients, required skills to enhance family members’ competency in caregiving, and factors that may challenge the stability of relationships post-injury. Specifically, the elements of support needed by SCI family caregivers based on the findings included: personal attendant support, home care professional/medical support, respite, psychosocial support, and information/training.

Furthermore, the importance of increasing support (e.g., access to home and community care services) for caregivers of high needs/complex individuals with SCI (e.g., tetraplegic, older individuals) was also emphasized. Building on the findings of this study, future research is needed in determining specific intervention/program needs of SCI family caregivers at each stage of the caregiver-care recipient journey. Collectively, this research enhanced our understanding of a population that is often neglected in research and in the rehabilitation process and, in doing so, outlined opportunities for enhanced support that can promote sustained caregiving as well as improve the health outcomes of both individuals with SCI and family caregivers.
Candidate’s Role

The candidate (GJ) conceived all research objectives addressed in this thesis, developed the study protocol with contributions from thesis committee (Dr. Susan Jaglal, Dr. Cathy Craven, and Dr. Jill Cameron), recruited the participants/liaised with the Rick Hansen Institute, Spinal Cord Injury Ontario and TRI-Lyndhurst Centre to recruit the participants, conducted all interviews, completed all data analysis, and wrote the dissertation.
References

[Chapter 1 and 2]


Marini, M. G., & Reale, L. (2010). Bisogni e costi delle persone con lesione midollare e dei nuclei familiari di riferimento. IAS.


[Chapter 3]


Marini, M. G., & Reale, L. (2010). Bisogni e costi delle persone con lesione midollare e dei nuclei familiari di riferimento. IAS.


Marini, M. G., & Reale, L. (2010). Bisogni e costi delle persone con lesione midollare e dei nuclei familiari di riferimento. IAS.


[Chapter 5]


[Chapter 6]


[Chapter 7]


[Chapter 8]


Lum, J., Sladek, J. & Ying, A. (2010). Home Support Workers in the Continuum of Care for Older People, Toronto: Canadian Research Network for Care in the Community.


Appendix A

Research Ethics Board Approvals

[Image of a document titled "Notification of REB Initial Approval" with details on the approval process, including dates and documents approved.]
PROTOCOL REFERENCE # 33202

June 23, 2016

Dr. Susan Jaglal  
DEPT OF PHYSICAL THERAPY  
FACULTY OF MEDICINE

Ms. Gayathri Jeyathevan  
DEPT OF PHYSICAL THERAPY  
FACULTY OF MEDICINE

Dear Dr. Jaglal and Ms. Gayathri Jeyathevan,

Re: Administrative Approval of your research protocol entitled, "Implementation considerations for a spinal cord injury caregiver support program"

We are writing to advise you that the Office of Research Ethics (ORE) has granted administrative approval to the above-named research protocol. The level of approval is based on the following role(s) of the University of Toronto (University), as you have identified with your submission and administered under the terms and conditions of the affiliation agreement between the University and the associated TAHSN hospital:

- Graduate Student research - hospital-based only
- Storage or analysis of De-identified Personal Information (data)

This approval does not substitute for ethics approval, which has been obtained from your hospital Research Ethics Board (REB). Please note that you do not need to submit Annual Renewals, Study Completion Reports or Amendments to the ORE unless the involvement of the University changes so that ethics review is required. Please contact the ORE to determine whether a particular change to the University's involvement requires ethics review.

Best wishes for the successful completion of your research.

Yours sincerely,
Appendix B

Letter of Invitation to Participate in the Study

Implementation Considerations for a Spinal Cord Injury Caregiver Support Program

Dear Sir/Madam,

This letter is an invitation to participate in a research study about caregivers of individuals with spinal cord injury (SCI). I will be conducting interviews with caregivers and care recipients as part of my doctoral work at the University of Toronto in the Department of Health Policy, Management and Evaluation. My goal is to better understand the various family (spouse and parent) caregiver roles, and the skills needed in providing support to individuals with spinal cord injury (SCI).

In particular, I am interested in talking to people who have sustained a spinal cord injury either within the past 2 years OR at least 10 years after discharge from inpatient rehabilitation. I hope to talk to participants about the challenges they face, and the type of help needed by caregivers in providing care. Our team’s overall project goal is to develop a skills training program for family caregivers of individuals with SCI.

To participate in the study, you must be:

1) **someone with spinal cord injury** (SCI) who
   - is 18 years of age or older
   - was discharged from inpatient rehabilitation less than 2 years ago OR more than 10 years ago
   - is fluent in English

or
2) a spouse or parent of someone with SCI who was discharged from inpatient rehabilitation less than 2 years ago OR more than 10 years ago and
   • to whom you provide physical and/or psychological/emotional support
   • with whom you have regular (i.e., at least weekly) contact
   • you are fluent in English

*Note*: I prefer both the individual with SCI and his/her family member/caregiver to participate in this study. However, if only one individual (either the individual with SCI or family member) can participate, I welcome that individual to participate solely.

If you decide to participate, you and your caregiver will be asked to engage in a separate telephone interview in the comfort of your own homes. You will be compensated as an expression of gratitude for taking your time to participate in the study. If you orally consent to provide your contact information to learn more about the study, I will be mailing you the written consent form and then contact you to answer any questions/concerns you may have about the study. If you decide later not to hear more about the study or to be contacted by the research team, please feel free to email/call the student investigator to inform her.

Thank you very much for your consideration. If you are willing to participate or if you have any study related questions, please contact the student investigator Gaya Jeyathevan at 905-903-8019 416-978-0315, or email gaya.jeyathevan@mail.utoronto.ca. With your help we can meet the study goals, creating a better health care system for you and the community. I very much look forward to speaking with you and thank you in advance for your assistance in this project.

With kind regards,

Signature

Gaya Jeyathevan
PhD Candidate
Department of Health Policy, Management & Evaluation
University of Toronto
Appendix C

Consent Form

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

Study Title:
Implementation Considerations for a Spinal Cord Injury Caregiver Support Program

Principal Investigator:
Dr. Susan Jaglal, PhD
Telephone Number: 416-978-0315

Sponsor:
This research study has been funded by Craig H. Neilsen Foundation

Introduction:
You are being asked to take part in a research study. Please read the information about the study presented in this form. The form includes details on study’s risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study doctor or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

Background/Purpose:
Previous findings from our parent study suggest that family caregivers play a significant role in providing physical and emotional support to individuals with SCI, which results in significant caregiver burnout. Family caregivers of persons with spinal cord injuries (SCI) take on many roles. Caregivers are thrust into this new caregiving role without any preparation or training, which may lead to caregiver strain. Despite the growing awareness of the roles of family caregivers, surprisingly little is known about the skills needed in providing continued care for individuals with SCI. The purpose of this research study is to better understand the various
family (spouse and parent) caregiver roles, and the skills needed in providing support to individuals with spinal cord injury both in the early period after discharge (within the past 2 years) and as time goes on (10 years or more) post-discharge from inpatient rehabilitation. This study will investigate the experiences and perspectives of both the individuals with SCI and their family members. The study will further seek to determine the challenges as well as the types of help needed by family members in providing care. Our overall goal is to develop a skills training program for family caregivers of individuals with SCI. You are being asked to participate because you are an individual with SCI who has a family member (either a spouse or parent) providing care to you and/or you are a family member (either a spouse or parent) providing care to an individual with SCI.

**Procedures:**

You are asked to participate in a telephone interview lasting approximately 60 minutes. Interviews will be done separately to determine the various roles of the family member providing care, the skills needed in providing support to the individuals with SCI, and the challenges as well as the type of help needed by caregivers in providing care.

**Risks:**

Taking part in this study has risks. Some of these risks we know about. There is also a possibility of risks that we do not know about and have not seen in humans to date. Please call the study doctor (Gaya Jeyathevan) if you have any side effects even if you do not think it has anything to do with the study.

The risks we know of are:
- Possible psychological risks such as anxiety, distress, or feelings of sadness that may arise from the interviews about sensitive issues (e.g. caregiver burden)

If you feel uncomfortable answering certain questions, you may wish to not answer without having to provide any reason.

**Benefits:**

You may not receive direct benefit from being in the study. Information learned from this study may help provide a better understanding of the caregiver experiences and skills needed to take care of the individual with spinal cord injury (SCI) within 2 years and after 10 years post-discharge. Your participation will also provide evidence to develop a SCI caregiver support program on a national level.

**Confidentiality:**

If you agree to join this study, the study doctor and her study team will look at your personal health information and collect only the information they need for the study. Personal health information is any information that could identify you and includes your:
- Name
- Phone number
- Address
- Date of birth (year only)
- Family members’ names
- Health information (related to the inclusion criteria)

The following people may come to the hospital to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study is following proper laws and guidelines:

Representatives of the University Health Network (UHN) including the UHN Research Ethics Board

Your anonymity and confidentiality are treated with respect and will be protected at all times. Names and identifying information will be restricted and kept confidential at all times. ID codes will be used as an identifier, as well as to keep all the names disclosed. The study doctor will keep any personal health information about you in a secure and confidential location for 10 years. A list linking your study number with your name will be kept by the study doctor in a secure place, separate from your study file. Audio recordings will be retained and intact for one year (until the research is complete). During the retention period, all audio recordings will be held in strict confidence and stored securely in password protected files (on University maintained servers). Any data in paper format will be shredded, and data in electronic format will be destroyed by reformatting, rewriting or deleting. 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. All information collected during this study, including your personal health information, will be kept confidential and will not be shared with anyone outside the study unless required by law. Your participation in this study will also be recorded in your medical records at this hospital. This is for clinical safety purposes. You will not be named in any reports, publications, or presentations that may come from this study.

**Voluntary Participation:**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without any penalty. We will give you new information that is learned during the study that might affect your decision to stay in the study. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.

**Withdrawal from the Study:**

You can withdraw from the study at any time, for any reason, if you decide. If you decide to withdraw, you will still be eligible to receive the promised compensation for agreeing to be in the study. If you decide to leave the study, you have the right to request withdrawal of information collected about you. Let your study doctor know.

**Costs and Reimbursement:**
You do not have to pay for any of the procedures involved in the study. Participants will be compensated $25 CAN (in gift card) per person in recognition of the time required to participate in the current study.

**Rights as a Participant:**

If you are harmed as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost.

By consenting to this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

**Conflict of Interest:**

Craig H. Neilsen Foundation, the sponsor of this study, will reimburse the hospital and researcher for the costs of doing this study. All of these people have an interest in completing this study. Their interests should not influence your decision to participate in this study.

**Questions About the Study:**

If you have any questions, concerns or would like to speak to the study team for any reason, please call: Study Doctor at 416-978-0315.

If you have any questions about this process, or about your rights as a participant in the study, please contact the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

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**For the Interviewer**

**Consent:** This study has been explained to the participant and any questions he/she had have been answered. The participant is aware that he/she may leave the study at any time. The participant has agreed to allow the investigators on the team to use the information he/she provided as described in this form. The participant has also agreed to allow the interviewer to record the phone interview. *(Participant's name)*, has orally consented to participate in the SCI Caregiver Support Study conducted by Gaya Jeyathevan, PhD (c). The signature below from the interviewer indicates the participant’s oral consent to participate in this study.

Signature: ____________________  Printed Name: ____________________  Date: _________________
RESEARCH:

Implementation Considerations for a SCI Caregiver Support Program

Objective: To understand the various family (spouse and parent) caregiver roles, and the skills needed in providing support to individuals with spinal cord injury (SCI) both 1) in the early period (between 3 months to 2 years post-discharge from inpatient rehabilitation), 2) as time goes on (after 10 years post-discharge from inpatient rehabilitation). This study will include the experiences and perspectives of both the individuals with SCI and their family members. The study will further seek to determine the challenges as well as the type of help needed by family members in providing care.

☐ Patient has orally consented to the following personal health information and contact information being forwarded to a research team member for this study, and being approached with more information about the study.

Signature of Healthcare Professional

Date

<table>
<thead>
<tr>
<th>Pre-screening Criteria</th>
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<tbody>
<tr>
<td><strong>Yes</strong></td>
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Appendix E

Patient Referral Form for Family Members/Caregivers

RESEARCH:

Implementation Considerations for a SCI Caregiver Support Program

Objective: To understand the various family (spouse and parent) caregiver roles, and the skills needed in providing support to individuals with spinal cord injury (SCI) both 1) in the early period (between 3 months to 2 years post-discharge from inpatient rehabilitation), and 2) as time goes on (after 10 years post-discharge from inpatient rehabilitation). This study will include the experiences and perspectives of both the individuals with SCI and their family members. The study will further seek to determine the challenges as well as the type of help needed by family members in providing care.

☐ Family member/caregiver has orally consented to the following personal health information and contact information being forwarded to a research team member for this study, and being approached with more information about the study.

__________________________  ____________________
Signature of Healthcare Professional  Date

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<th>No</th>
<th>Don’t Know</th>
<th>Criteria</th>
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<tr>
<td>He/she is a family member (spouse or parent) of an individual with SCI</td>
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<td>☐</td>
<td>☐</td>
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</tr>
<tr>
<td>He/she is providing physical and/or psychological support to the individual with SCI</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>He/she is fluent in English</td>
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</table>
SCI CAREGIVER SUPPORT STUDY

RESEARCH PARTICIPANTS NEEDED!

We are looking for **individuals with spinal cord injury (SCI)** who:

- Are 18 years of age or older
- Have a SCI
- Have been discharged from inpatient rehabilitation less than 2 years ago **OR** more than 10 years ago
- Are fluent in English

We are also looking for **family members/caregivers of individuals with SCI** who was discharged from inpatient rehabilitation less than 2 years ago **OR** more than 10 years ago who:

- Are spouses or parents of the individuals with SCI
- Provide physical and/or psychological/emotional support to the individuals with SCI
- Have regular contact with the individuals with SCI (i.e., at least once a week)
- Are fluent in English

*Note: We prefer both the individual with SCI and his/her family member/caregiver to participate in this study. However, if only one individual (either the individual with SCI or family member) can participate, we welcome that individual to participate solely.

The purpose of this research study is to better understand the various family (spouse and parent) caregiver roles, and the skills needed in providing support to individuals with spinal cord injury (SCI) within 2 years and 10 years after discharge from inpatient rehabilitation. The study
will further seek to determine the challenges as well as the type of help needed by caregivers in providing care. Our overall goal is to develop a skills training program for family caregivers of individuals with SCI.

Participants will take part in a telephone interview that lasts approximately 60 minutes. Each participant will be compensated.

**Contact Information**

Gaya Jeyathevan, PhD Candidate

Department of Health Policy, Management & Evaluation- University of Toronto
Appendix G

Oral Consent Script

Good afternoon. May I please speak with <Participant’s name>?

Hello <Participant’s name>. My name is Gaya Jeyathevan, and I am calling about the SCI Caregiver Support Study. I understand you may be interested in participating in our study. Is that correct?

If response is “yes”, proceed; if response is “no”, thank the individual and end the call.

If response is “maybe” or “I’m not sure”, ask whether you can answer any questions or provide more information.

I’m conducting this research as part of my doctoral thesis at University of Toronto. I’m working under the supervision of Dr. Susan Jaglal of University of Toronto’s Institute of Health Policy, Management and Evaluation.

Have you received the written information package about the study?

If response is “no”, then get the individual’s email/mail address to send the information package; and inform him/her that you will call back (variable days depending on mailing procedure) to do the interview.

I just want to tell you a little bit about this study. The purpose of this research study is to better understand the various family (spouse and parent) caregiver roles, and the skills needed in providing support to individuals with spinal cord injury (SCI) within 2 years and after 10 years after discharge from inpatient rehabilitation. The study will further seek to determine the challenges as well as the type of help needed by family members in providing care. Our overall goal is to develop a skills training program for family caregivers of individuals with SCI. This telephone interview will take about 60 minutes. I will also interview your family member (either the individual with individual or family caregiver) later on (if applicable).

Before we start, I would like to go over some of the details of the information package you received. Your participation in this study is voluntary. There are no known risks associated with you participating in this interview. However, if you feel uncomfortable answering certain questions, you may wish to not answer without having to provide any reason. All you need to do is ask me to skip the question. If at any time during the interview you would like to pause or stop, please say so. You may also wish to withdraw from the study at any point by telling me or anyone on the research team. If you decide to withdraw from the study, all information you have provided will be destroyed immediately wherever possible.
As soon as the interview is complete, the digital audio recording will be assigned a unique ID number. Your name and any identifying information that is unintentionally recorded will be taken off the transcripts of our conversation and replaced with your unique ID. Names and identifying information will be restricted and kept confidential at all times. Confidentiality will be provided to the fullest extent possible by law. 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.

This phone interview will be recorded and I want to make sure that you are comfortable for me to do so. Are you comfortable with me recording this telephone interview?

*If response is “yes”, proceed; if response is “no”, stop recording and take notes.*

**Do you have any questions?** Yes / No

**Can you please state your name for the recording?** [Wait for response; if he/she does not want his/her name to be recorded, stop recording and take notes]

**Have you read the consent form?** [Wait for confirmation; if “no”, read the consent form]

**Do you understand the information on the consent form, and that I have discussed with you today?** Yes / No

**Have your questions about the study, and the consent process, been answered to your satisfaction?** [Wait for confirmation; if “no”, address additional questions]

**Do you need any other information before you can decide to participate?** [Wait for confirmation; if “yes”, address additional information needs]

**Do you agree to participate in this study?** Yes / No

I am now signing and dating a physical copy of the consent form that I mailed to you beforehand in order to verify that I have obtained your oral consent to participate in this research study. If you would like, I can provide you with an electronic or hard copy of my signature on this form. You can also request a copy of the consent form that I have signed at any point, and it will be provided it to you.

**Would you like me to do this for you?** Yes / No
Appendix H
Caregiver Interview Guide

A. Background Information

- Welcoming the participants, providing a brief overview of the interview and its purpose, and stating the ground rules of the interview.
- Go over consent form, explain how confidentiality and anonymity will be protected. Ensure the participants understand/agree with everything on the consent form, and have them orally agree to participate (See Appendix F for oral consent script).

B. Establishing Rapport/Demographic Information

- Can you tell me about yourself please? (i.e., age, geographic location-urban or rural, how are you related to your family member with the SCI? How did you become the primary person to assist your family member? How long have you been providing care? Are you a healthcare provider?).
- Can you tell me about the family member you are taking care of? (i.e., age, type/level of injury, cause of injury, time since injury, time since discharge from inpatient rehab).

C. Interview Questions (focusing on TDF)

1. Can you walk me through what you are currently doing to assist your family member with SCI on a daily basis?
   - Probing: How do you provide physical assistance?
   - Probing: How do you provide emotional support?
   - Was there any incident where you felt a certain caregiving task was difficult to do? Why?

*Questions 2-5 are for the less than 2 years post-discharge group only:

Knowledge:

2. During Rehab: Can you please explain if you were provided with any training or information on how to assist your family member while he/she was in the rehabilitation centre?
   - a. Probing: What kind of training did you have (i.e., bowel/bladder management, wound care, nutritional information)?
   - b. Probing: How was this training provided to you (i.e., online, in-person, video instruction, one-on-one training/educational sessions with healthcare provider, self-directed, etc.)?
   - c. Probing: Was the training useful? Why or why not?
   - d. Probing: Were you able to apply this training after you returned home? And how?
   - e. What kind of training did you feel you needed to have during rehab?

3. Transition from Rehab to Community: Were you provided with any training or information on how to assist your family member after he/she had returned back home (after discharge from rehab centre)?
   - a. Probing: What kind of training did you have?
   - b. Probing: How was this training provided to you?
c. Probing: What kind of training did you need to assist your family member with SCI just after returning home?

4. **3 months- 2 years post-discharge:** Are you currently receiving training to assist your family member with SCI?
   a. Probing: What kind of training are you currently receiving?
   b. Probing: How is this training being provided to you?
   c. Probing (*if they say no to main question*): What kind of training did you receive recently?
   d. Probing: What kind of training or information do you require now that it has been around 2 years?

*Question 5 is for the 10 years post-discharge group only:*

5. Are you currently receiving training to assist your family member with SCI?
   a. Probing: What kind of training did you have?
   b. Probing: How was this training provided to you?
   c. Probing (*if they say no to main question*): What kind of training did you receive recently or in the past?
   d. Probing: What kind of training or information do you require now?
   e. Probing: Have the training or information needs to provide care changed due to the aging of your family member with SCI?

**Beliefs about Capabilities and Consequences:**

6. What are some things that have helped you in providing care to your family member (i.e., other family members, community support services, educational materials, etc.)?
7. What are some things that have hindered you in providing care to your family member (i.e., other family members- dual roles, work, etc.)?
8. What do you feel are the consequences of you not providing care to your member?
9. What do you think are some benefits of you, as a family member, providing care to your family member with SCI, as opposed to say for example a paid caregiver?

**Skills:**

10. What are some skills (whether it be practical or emotional) you currently use or have developed over time in assisting your family member (can you please provide some examples)?
    a. Probing: How and when did you gain these skills?
    b. Probing: Considering the skills you have to care for your family member, what are some consequences or challenges you are facing by not necessarily having all of the appropriate skills?

11. What are some skills, if any, you feel you need to learn so as to provide better care for your family member?

**Social Influences:**

12. How do family members, friends, and/or health care providers help you with your caregiving roles or to develop your skills?
13. Are there any ways that your family, friends, and/or health care providers could be more helpful (with caregiving roles or to develop your skills)?
14. How does providing care to your family member impact your other roles as a mother/father, spouse, active community member, etc.?

**Environmental Context & Resources:**
15. Does your family member receive any community health care services (such as from a Community Care Access Centre or an independent third party caregiver)?
   a. Probing: Who pays for these health care services?
16. How do/did these services help you in providing care to your family member?
17. Are there any community supportive care services or hospital services available to you to develop your skill needs? If so, please explain.
   a. If not, what are some barriers you are facing in obtaining the skills training you need to provide support to your family member with SCI? (i.e., lack of access to community supportive care services, time, money, etc.)
   b. Probing: Are you using any electronic resources, such as internet or a phone application, that provides information on how to assist your family member better on a daily basis or to develop your skills?
   c. Probing: What could health care providers or community health services do to help you assist your family member on a daily basis or help you develop your skill needs?

**Emotion:**

18. How does providing care to your family member affect you emotionally (positively and negatively)?
   a. Probing: Do you have any negative emotions (i.e., frustration, stress, depression) when providing care to your family member?
   b. Probing: How do you handle negative emotions when providing care to your family member?
   c. Probing: Do these emotions hinder you from providing the care needed by your family member? If so, how?
   d. Probing: How could we help you handle your emotions (i.e., stress, frustration, fatigue) better?

**D. Wrap-up Questions**

19. Is there anything else I haven’t asked you about that you would like to add?
20. If you could provide advice to somebody else who is just stepping into this caregiving role, what would you tell them?
21. If you could make one change to help people with SCI and their families, what would it be?
22. If I have any further questions or if you have anything else to add, can we please contact each other again? Also, if you think of anything you would like to add, please do contact me.
Appendix I
Care Recipient Interview Guide

A. Background Information
- Welcoming the participants, providing a brief overview of the interview and its purpose, and stating the ground rules of the interview.
- Go over consent form, explain how confidentiality and anonymity will be protected. Ensure the participants understand/agree with everything on the consent form, and have them orally agree to participate (See Appendix F for the oral consent script).

B. Establishing Rapport/Demographic Information
- Can you tell me about yourself please? (i.e., age, geographic location - urban or rural, type/level of injury, cause of injury, time since injury, time since discharge from inpatient rehab).
- Can you tell me about the person or people in your family who help you out with things on a regular basis? (i.e., age, relationship to you, how they became the person to help you, how long have they been assisting you etc.).

E. Interview Questions (focusing on TDF)

1. Can you explain to me how your family member assists you on a daily basis?
   a. Probing: How does he/she provide physical assistance?
   b. Probing: How does he/she provide emotional support?
   c. Probing: Is there anything that you would like more assistance with? Or less assistance? Why or why not?
   d. Was there any incident where your family member felt a certain caregiving task was difficult to do? Why?

*Questions 2-4 are for the less than 2 years post-discharge group only:

Knowledge:
2. During Rehab: Can you please explain if your family member was provided with any training or information on how to assist you during your discharge from the rehabilitation centre?
   a. Probing: What kind of training did he/she have (i.e., bowel/bladder management, wound care, nutritional information)
   b. Probing: How was this training provided to him/her (i.e., online, in-person, video instruction, one-on-one training/educational sessions with healthcare provider, self-directed, etc.)?

3. Transition from Rehab to Community: Can you please explain if your family member was provided with any training or information on how to assist you after you had returned back home (after discharge from rehab centre - within the first month)?
   a. Probing: What kind of training did he/she have?
   b. Probing: How was this training provided to him/her?
   c. Probing: What kind of training did you think your family member needed to assist you with just after returning home (i.e., self-care activities- symptom management, skin checks)?
4. **3 months- 2 years post-discharge**: Is your family member currently receiving training to assist you?
   a. Probing: What kind of training is he/she receiving?
   b. Probing: How is this training being provided to him/her?
   c. Probing (*if they say no to main question*): What kind of training did he/she receive recently?
   d. Probing: What kind of training do you think your family member needs to assist you SCI currently?

*Question 5 is for the 10 years post-discharge group only:*
5. Is your family member currently receiving training currently to assist you?
   a. Probing: What kind of training is he/she receiving?
   b. Probing: How is this training being provided to him/her?
   c. Probing (*if they say no to main question*): What kind of training did he/she receive recently or in the past?
   d. Probing: What kind of training or information does your family member require now to assist you?
   e. Probing: Do you think the training or information needs to provide care to you changed as you and your family caregiver aged? How so?

**Beliefs about Capabilities and Consequences:**
6. From your perspective, what are some things that have helped (or may help) your family member in providing care to you (i.e., other family members, community support services, educational materials, etc.)?
7. From your perspective, what are some things that have hindered (or may hinder) your family member in providing care to you (i.e., other family members- dual roles, work, etc.)?
8. From your perspective, what do you think are some benefits of your family member being the primary caregiver?
9. From your perspective, what do you think are some drawbacks of your family member being the primary caregiver? (i.e.,

**Skills:**
10. What are some skills (whether they be practical or emotional) your family member currently uses or has developed over time in providing care to you (can you please provide some examples)?
    a. Probing: Considering the skills he/she has to assist you, what are some challenges do you think he/she is facing by not necessarily having all of the appropriate skills?
11. What are some skills you feel your family member would benefit from learning to be able to provide better care for you?

**Social Influences:**
12. How do family members, friends, and health care providers help your family member (i.e., with the caregiving duties or to develop the skills he/she needs)?
13. Are there any ways that your family, friends, and health care providers could be more helpful to your family member?
14. From you perspective, how does assisting you impact your family member’s roles as a mother/father, spouse, active community member, etc.?

**Environmental Context & Resources:**
15. Do you receive any community health care services (such as from a Community Care Access Centre or an independent third party caregiver- paid attendant caregiver)?
   a. Probing: Who pays for these health care services?

16. Do you think these services help your family member in providing care to you? If so, how?

17. Are there any community supportive care services or hospital services available for your family member to develop his/her caregiving skill needs? If so, please explain.
   a. If not, what are some barriers he/she is facing in obtaining the skills training he/she needs to assist you? (i.e., lack of access to community supportive care services, time, money, etc.)
   b. Probing: Is your family member using any electronic resources, such as internet or a phone application, that provides information on how to assist you better on a daily basis or to develop his/her skills?
   c. Probing: What could health care providers or community health services do to help your family member assist you better on a daily basis or to develop his/her skills?

Emotion:

18. How do you think providing care to you affects your family member emotionally (positively and negatively)?
   a. Probing: Does he/she show any signs of negative emotions (i.e., frustration, stress, depression) when providing care to you?
   b. Probing: How does he/she cope with or handle these emotions?
   c. Probing: How do you help your family member cope with these negative emotions when providing care to you?

F. Wrap-up Questions

19. Is there anything else I haven’t asked you about that you would like to add?
20. If you could provide advice to somebody else who is just stepping in the caregiving role, what would you tell them?
21. If you could make one change to help people with SCI and their families, what would it be?
22. If I have any further questions or if you have anything else to add, can we please contact each other again? Also, if you think of anything you would like to add, please do contact me.
Appendix J

Codebook

Codes for Support Needed by CRs:

<table>
<thead>
<tr>
<th>Construct</th>
<th>Code</th>
<th>Description</th>
<th>Example</th>
<th>Representative Quote</th>
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</thead>
<tbody>
<tr>
<td>Practical</td>
<td>Self-care/Basic ADL support</td>
<td>Support provided with self-care activities</td>
<td>Bathing, dressing, transferring, personal hygiene/grooming, bowel/bladder care (catheterization/digital stimulation/suppository)</td>
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<tr>
<td>Instrumental ADL support</td>
<td></td>
<td>Support provided with tasks that add to the quality of life of individual with SCI, but not as basic to self-care</td>
<td>Preparing meals, housekeeping, transportation/driving, managing finances</td>
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</tr>
<tr>
<td>Secondary health conditions management</td>
<td>Support provided with assessing and managing specific injury related symptoms</td>
<td>Administrating/giving medications, bowel dysfunction management (colostomy bag), bladder infection management (UTI, autonomic dysreflexia), skin checks/pressure ulcer management, managing nutrition, exercises/stretching</td>
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<tr>
<td>Emotional Support</td>
<td>Providing Moral Support</td>
<td>Providing emotional or psychological support to CR</td>
<td>i.e. encouragement, i.e. confidence building, i.e. supporting CR personal autonomy</td>
<td>CR: “She’s really encouraging. She’s like, well, you know, try it this way, if that doesn’t work we’ll try something else, if not, I’m here.”</td>
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<td></td>
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<td></td>
<td>CG: “Ensuring that your children’s activities continue, extracurricular activities, and involving the person who is injured, too, is very important. That way, everybody feels together, and part of the whole process. Not alienated.”</td>
</tr>
<tr>
<td>Ensuring Social Interaction/Integration</td>
<td>Motivating the CR to get involved socially (as part of adaptation to SCI)</td>
<td>i.e. encouraging/supporting the CR’s personal/relational identity (focus as a parent)</td>
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<td></td>
<td></td>
<td>i.e. bringing all family members together</td>
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<td></td>
<td></td>
<td>i.e. empowering CR to be a productive member in</td>
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<tr>
<td>Community (becoming a peer mentor)</td>
<td>i.e. encouraging/supporting CR to participate in recreational/leisure activities</td>
<td>CG: “I've also encouraged him (CR) to be with a seniors’ group and that too. He sings in a choir with the seniors and things like that.”</td>
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</table>
| Advocacy | Communicating on behalf of the CR; to act like the bridge between the healthcare system and the CR | i.e. understanding/being aware of CR’s needs and concerns, and communicating and seeking solutions from healthcare professionals in a timely manner to get, i.e.:  
- health care (symptom management options)  
- community resources (assistive devices)  
- emotional support (counseling) | CG: “He (CR) has some problem in his hip so today he had an appointment so I talked to his sitting clinic, and they gave me some advice so we will do those ones.” |
## Codes for Facilitators and Barriers:

### Facilitators to Providing Care

<table>
<thead>
<tr>
<th>Construct</th>
<th>Code</th>
<th>Definition</th>
<th>Example</th>
<th>Representative Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Community Support Services</td>
<td>Professional Services</td>
<td>Services provided by licenced health care professionals to CR with respect to providing mostly health/medical related assistance/information</td>
<td>i.e. physiotherapy services (in home services)</td>
<td>CG: “There’s supportive living services in Bolton, visiting volunteers, like, I can have someone come in and watch him while I go to the store, Respite Care, sponsored housing, traditional care, transportation. They asked me if I want these things. Well, they have visiting volunteers…”</td>
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<tr>
<td></td>
<td>Personal Support/Attendant Services</td>
<td>Services provided by an unregulated health care worker to CR with respect to providing mostly ADL/self-care related assistance</td>
<td>i.e. basic attendant services (support with basic and instrumental ADL)</td>
<td>CR: “We were both resistant in having strangers coming into our home when it first happened. So he (CG) was helping, and it was not a good thing. Looking back, I would have put it in right away. So as soon as they (PSWs) came in and they started, it helped alleviate all the caregiving responsibilities that he felt he had. So it was much better for our relationship.”</td>
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<tr>
<td></td>
<td>Day Services</td>
<td>Services provided to CR during the day with social support or community integration</td>
<td>i.e. transportation services (Wheel Trans)</td>
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<td>i.e. respite care</td>
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<td>Positive Coping in Relationship</td>
<td>Positive Individual Attitude/Behaviour</td>
<td>CR or CG showing attributes of positive attitude or behaviour in relationship which enables providing care effectively (and with less difficulty)</td>
<td>i.e. CR’s positive attitude/behaviour (independent, appreciative)</td>
<td>CG: “If you’re having to give up something on your schedule, in order to provide care on the home front, then you can feel a little bit of stress on that level. On the other hand, you are helping out somebody that you love, which gives you a feeling of satisfaction, too.”</td>
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<td></td>
<td>i.e. CG’s positive outlook on life (optimism) or positive attitude (having sense of humour) in order to cope with caregiving role</td>
<td>CR: “I do a little bit of laundry, like I put the stuff in the washer and transfer it to the dryer, but she folds the clothes because I really hate folding clothes. If she has a faucet leak, then I’ll fix that,”</td>
</tr>
</tbody>
</table>
| Positive Dyadic Coping | Affective relationship between CG and CR as involving closeness/intimacy, interdependence, and instrumental aid/interpersonal exchanges | i.e. mutuality & reciprocity:  
- interdependence (shared activities-assistance with house chores)  
- communicating empathy  
- mutual respect for each others’ needs | so there’s stuff like that. So, we trade back and forth that way.” |
| --- | --- | --- | --- |
| Social Support | Family and Friends Support | Support provided by informal networks, typically with a closer relationship with the CG | i.e. instrumental (housekeeping, babysitting if CG is a young parent)  
- i.e. emotional (comfort)  
- i.e. informational (advice)  
- i.e. appraisal (providing feedback) |
| Peer Support Group | Support provided by informal networks, consisting of individuals who share a common experience (mostly caregivers) | i.e. informational (advice)  
- i.e. appraisal (providing feedback)  
- i.e. emotional (moral support) |
| Mastery of Caregiving Roles | Caregiver Confidence | Having a positive view of caregiver’s ability to undertake (and sustain) caregiving tasks | i.e. satisfaction with own performance as CG  
- i.e. feeling in control of care situations |

CG: “As a caregiver, you have to be able to have your own reprieve as well, so I always made sure that I was able to get away for a little bit of time on the weekend. That’s where his mother would help.”

CG: “Sometimes we need a peer mentor. And if you hear a different way of doing something, maybe we could try that...You talk about things that you don’t talk about in public. And then just in conversation you can learn something new. It can give you an idea or you realize that someone else goes through the same thing. This is how they deal with it. Or you can give advice.”

CG: “I’ve learned everything, and any changes that come up, I’ll learn them. I will be the one that’s with him at the doctor when she says or he says, you need to do this or you need to do that. I’m going to be the one that gets that news, so I’m going to learn how to do it. They’ll explain it and then we’ll go home and try it.”
<table>
<thead>
<tr>
<th>Construct</th>
<th>Code</th>
<th>Definition</th>
<th>Example</th>
<th>Representative Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of Access to Community Resources</td>
<td>Lack of Access to Funding</td>
<td>Not having access to necessary funds to provide assistance to CR i.e. limited funding for: third party caregiver, assistive technology, home modifications</td>
<td>i.e. electronic wheelchairs i.e. advanced hoyer lifts i.e. advanced summer/winter wheelchair tires</td>
<td>CG: “We’re lacking the funding and the information. We don’t know if they did come up with anything new. And yes, lacking the funding, that’s a big issue there. If we did have the information, which we don’t ... but just say we did have the information, if there is anything new that comes up, then we also need the funding to go with it.” CR: “I need a new mattress and the problem there is finances are not available for it. The unfortunate thing is mattresses or hospital beds are not exactly on the cheap list, I would be looking at probably about $3,000 to get a proper mattress so it’s not going to happen in the near future unfortunately. It’s why my wife and I are not legally married because of finances, we would lose too much money. It’s crazy but it’s true.”</td>
</tr>
<tr>
<td>Lack of Access to Assistive Devices</td>
<td></td>
<td>Not having access to relevant (and evolving/new) assistive devices for CR</td>
<td>i.e. emotion coaching: how to approach the CR, being aware of CR emotions, emotional coping strategies, emotional/behaviour</td>
<td>CG: “It would be nice to know what is new out there concerning spinal cord injuries, if it’s free. How we go about getting into anything like that ... it’s hard. We can find it, but it’s usually ... everything is down in the States or China or some place like that. Unless we have something here in Canada”</td>
</tr>
<tr>
<td>Limited Formal Training for Caregivers</td>
<td>Limited Formal Training for Caregivers</td>
<td>Limited training provided by professional healthcare providers to CGs during rehab or at an ongoing basis</td>
<td>i.e. emotion coaching: how to approach the CR, being aware of CR emotions, emotional coping strategies, emotional/behaviour</td>
<td>CG: “I hate to say, is seriously ... unless you know someone in there (rehab centre), there is no sense of them having that (training) for spinal cord injuries. We were doing the same thing over and over and over again. I was looking things up and I said, oh, can we try this, a little bit of progress instead of the same thing every day.”</td>
</tr>
<tr>
<td>Lack of Knowledge on Available Community Resources</td>
<td>Lack of knowledge on where and how to access available community resources</td>
<td>i.e. home care, assistive devices, funding programs</td>
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<td>CR: “I would have liked him to know what an actual spinal cord injury is, and the emotions and cycles that people go through. Because I wasn’t comfortable explaining it to him, but I would have loved someone else to explain it.”</td>
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<td>CG: “Because there is so much information out there, I would say that is one of the real stumbling blocks that I am finding, that between the accident, the visiting, maintaining your home life and your work, and just trying to keep up with looking after his finances and his books and reporting to the Ontario Disability Support Program, there are so many things to think about. You just don’t know where to turn. Where do you go to find a personal support worker? Do you need to go through an agency or is it provided by the hospital or is that something the family is responsible for? There are so many questions and there are so many different websites to go on to. It’s almost...even that is overwhelming. So, it’s just difficult to navigate all of the information. It’s likely there, it’s just that we don’t know where to access, and how to access all of that.”</td>
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<tr>
<th>Fragmented Continuity of Care</th>
<th>Uninformed Primary Health Care Providers</th>
<th>Limited knowledge (particularly primary physicians, but sometimes rehab &amp; ER) of the clinical issues related to SCI and available supportive care services</th>
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<tr>
<td>CR: “The healthcare providers, if you tell them what the problem is, they’re just like, well, you’ve got to deal with it. They don’t give you options on where to call, what to do, anything.”</td>
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<td>CR: “Like a doctor would recommend something, and then I wouldn’t go along with it, because frankly, most doctors that we deal with don’t know what it’s like to deal with an SCI patient. So, some of the things that they would say were wrong.”</td>
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changes to expect in dyad  
  i.e. instrumental training: safe transfers after certain age, proper use of assistive devices  
  i.e. skills training: accessing resources & info, symptom assessment, when to step back from caregiving role
| Inconsistent/Uncoordinated Care; Limited Interpersonal Care | Perceived unsatisfactory quality of care/healthcare management provided by formal healthcare professionals to CRs and CGs over time | i.e. informational continuity: lack of timely, tailored information and advice provided to CR & CG (prognosis, symptom management)  

i.e. management continuity: mainly inconsistent management of a health condition that is not always responsive to a CR and CG’s changing needs (no ongoing comprehensive screening & needs/resources assessment)  

i.e. relational continuity: limited ongoing therapeutic relationship between healthcare providers and CR/CG (not easily accessible, communicating empathy and encouraging) | CR: “…they’re (physicians) not willing to say, oh, you need to call here, or try this place, they might be able to help. They don’t do anything like that. They get you (in) and get you out.”  

CG: “I mean, Stan Cassidy, that is our centre, they never call us. They never get an update to see how she is doing, or if something new has come up.”  

CG: “When he (CR) went to Sunnybrook Hospital, and the initial inspection of doctor, it was a surgeon, I think, orthopaedic surgeon which was looking at his spine, he called us and he said, I’m sorry to say, but there is no mobility in his body below shoulders, and there is not much we can do about it. My wife bluntly said, so what will he do with his life. Oh, he can watch television. My wife said, it means he will be a vegetable, and the doctor didn’t know what to say, but he said, yes.  

When Name-X (CR) was leaving West Park Hospital, and he was inviting people to his concert, he called his doctor and he said, this is the vegetable speaking. You can imagine, it makes me emotional, but you can imagine the satisfaction my wife and me have, that he got as far as he got.” |
|---|---|---|---|
| PSW Training | Added task (for CGs) of training personal support workers how to provide care to CR appropriately | i.e. instrumental training (safe transfers, personal bowel & bladder care)  

i.e. supervision of PSWs | CG: “I found that as we started getting PSWs in and support for Name-X (CR), I’m still the person that trains them. They sometimes come in not knowing what to do…because there are certain things that certain agencies don’t allow their PSWs to do, so I fill in those gaps.”  

CG: “We had cases where these people (PSWs) were … you couldn’t really say anything against them as they were not doing their job, but this was robot-like jobs. They didn’t develop a relationship on a personal level with these injured people. This is very important, that training for support worker should be also...” |
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<tr>
<th>Negative Coping in Relationship</th>
<th>Negative Individual Attitude/Behaviour</th>
<th>CR or CG showing attributes of negative attitude or disruptive behaviour in relationship resulting in difficulty in meeting caregiving roles</th>
<th>i.e. CR’s attitude/behaviour problems (uncooperative, aggressive) i.e. CG’s negative behaviour due to inability to cope with CR’s negative behaviour or caregiving tasks</th>
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<tr>
<td>CR: “Negatively, if I react and I’m not having a good day. She’s like, oh, not doing it no more.” CR: “She said, you’re just so angry, and I start moving or jumping around, and she doesn’t like that, or I start yelling at her.” – in context of tough caregiving task (bowel care)</td>
<td>CR: “…he (CR) want to occupy (exploit) me. He wants to occupy me, and what he can do himself, he wants me to do it, yeah.”</td>
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<tr>
<td>Negative Dyadic Coping</td>
<td>CR or CG supporting each other in a disapproving, uninspired, hostile, or patronizing way</td>
<td>i.e. co-dependency: one-sided relationship where typically: - CR relying too heavily on or has higher expectations of CG to meet nearly all of their needs; and - CG enabling or “caretaking” where he/she does for CR what that person should be doing for him/herself, allowing (enabling) the CR to continue the inappropriate behaviour i.e. controlling (from protection to control): CG may underestimate the CR’s abilities and assume responsibility for everything, diminishing the CR’s feeling of self-</td>
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<td>Caregiver Injury/ Illness</td>
<td>Poor Physical Health</td>
<td>Not being in a state of physical well-being, whereby CG is not physically fit to perform his/her daily activities without restrictions (as a result of caregiving or other external factors)</td>
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<td>i.e. progressive poor physical health due to caregiving (physical strain due transfers)</td>
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<td>i.e. sudden physical illness (flu)</td>
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<td></td>
<td>Caregiver Mental Health</td>
<td>Poor Mental Health</td>
<td>Having emotional distress and psychosocial impairment (as a result of caregiving or other external factors)</td>
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<td>Role Strain</td>
<td>Role Overload</td>
<td>Difficulty in meeting the demands of all caregiving roles by CG due to lacking of resources, including time and energy</td>
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<td>i.e. multiple diverse tasks, including caregiving, social and family related tasks</td>
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<td>Role Conflict</td>
<td></td>
<td>Difficulty in fulfilling caregiving role obligations/expectations by CG due to incongruity between the expectations of caregiver role and other social/relational roles</td>
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<td>i.e. caregiver obligations vs. work obligations (employee)</td>
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**CG:** “Actually, now I have some extra pain. I started some extra pains in my shoulders. At one time my shoulder was frozen full-time, and I couldn’t lift my shoulder. At that time, Name-X (CR) was saying help me to grab my hips on the bed. I told him I can’t do it. I have to do it, but I couldn’t so this made me aggressive, but aggression doesn’t count. It doesn’t help it, and also I gained so much weight. I also became depressive, and I am getting my depression medicine.”

**CG:** “Yeah, I feel very low. Actually, when he has some problem, physical problem, which he can’t handle, I also become so depressed I don’t want to wake-up from the bed.”

**CG:** “It was overwhelming, believe me, for like those six months... People say how do you do it, but I think you just do it, this is what I do. Other than the factor that I work double shifts, like when you’re in a setting like that and people come and go every eight hours, they work a shift, they go home. Other than that, there are some days I wish I had more help because I have to really organize my time.”

**CG:** “The last three years I had to bring my son. I had to drive him myself farther to Toronto. I was driving 60 kilometres further to a different school, a private school, because in this area the school was not good. So, every day I have to drive 100 kilometres. I have to take him and drop him there.”

- In the context of CG feeling depressed due to taking on multiple roles
<table>
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<tr>
<th>Construct</th>
<th>Definition</th>
<th>Code</th>
<th>Representative Quote</th>
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<tbody>
<tr>
<td>Monitoring and Managing Physical Health &amp; Secondary Health Conditions</td>
<td>Skills related to observing how the CR was doing to ensure that changes in the CR’s physical condition were noticed and appraise the changes (i.e. symptoms), keeping track of CR’s physical care needs, and managing multiple illness care needs in order to provide appropriate care</td>
<td>Using instruments to assess symptoms/signs appropriately</td>
<td>CG: “I got one of those little things (blood glucose test meter), I test his (CR) blood about every second day so his sugar is down to under 6 and it’s okay because he was up to 13.5 which is really high.”</td>
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<td>Paying attention to detail/noticing subtle physical changes</td>
<td>CG: “I know that he’s becoming autonomic dysreflexia and he starts to sweat, he gets nervous.” CG: “So, I check anyway, if there are any red marks, usually on her butt.” – signs of pressure sores</td>
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<td>Seeking explanations for unknown signs &amp; symptoms</td>
<td>CG: “…he (CR) said, I got rub burn from my sweater. I said, what do you mean? And I looked at it and I thought, I don’t know if that’s rub burn. And then we went in the condo and on the stove I could see a light there. And I was like, Name-X, did you make soup. He said, yeah. Okay, that’s what happened today, Name-X. Well, I guess he was stirring. Because he’s a quad, he might have feeling here but not here. So, I guess in that spot it didn’t bother him to have his elbow on the stove.”</td>
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<td>Medication management</td>
<td>CG: “I get his pills ready for seven days and I have a little dispenser and I just give him his pills, like morning, lunch time, supper time and night time.”</td>
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<td>Nutrition management</td>
<td>CG: “I constantly have to be aware that he does get constipated from the medication. I have to get a lot of greens into him and stuff that will make him go to the bathroom that I know moves him.”</td>
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| | | Taking into account multiple illness care needs of CR (i.e. other comorbidities- related to aging) | CG: “I make sure that he (CR) has his medications on time when he’s supposed to, because he has the beginning part of Alzheimer’s. It’s not as bad as what it is going to get, but he does frequently forget and so I
keep reminding him. And, if I’m not there, I phone him constantly, and at the times that I know he is supposed to have his medication and make sure he’s taking it. Most of the time ... a lot of times he remembers, but then there are times when he would forget.”

- In the context of managing meds for SCI because CR has both SCI and early AD-related to aging

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<tr>
<th>Making Decisions</th>
<th>Skills related to selecting a course of action based on CG’s careful observations and interpretation of the caregiving situation</th>
<th>Asssessing the importance of conflicting priorities/roles</th>
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<tr>
<td>CR: “A couple of weeks ago my grandfather ended up in the hospital and so mom couldn’t go up because she was here with me, and the lady (third party caregiver) was away...And then mom didn’t want to take me up to the hospital with her because everyone is sick up there and she didn’t want me to get sick and be stuck sitting up there all evening, so it’s little things like that that make it a hassle.”</td>
<td>CG: “The bed, safety-wise, has got to have a rail on it so that they don’t fall out because Name-X (CR) could have muscle spasms, even, in her sleep and that could make her fall out of bed. Now, I realize, okay, we have got to have a side up on the bed.”</td>
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<tr>
<td>Considering possible consequences of a decision and modifying decision as needed</td>
<td>Deciding when to step back from caregiving tasks</td>
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<td>CG: “She said if she couldn’t learn to way the proper way, then she wasn’t going to eat. So, I just put it in her fingers at first, lifted it through, and she learned to get it up there herself and now she can pick it up herself and do it.”</td>
<td>Deciding when to seek for informal social support</td>
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<td>CG: “I got my brothers and my brother-in-law, they came and built a ramp from the garage into the house. And then we built another ramp that went out the back door to the patio, so that he could go outside and enjoy the fresh air, so yeah, those sorts of things, rather than paying somebody to do all that. We solicited the help of family and we got it done, and it’s worked very well.”</td>
<td>Being Flexible</td>
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<td>Skills related to actively and continuously improving caregiving</td>
<td>Modifying house/environment to</td>
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<td>CG: “We wanted him (CR) home, but we didn’t have a home built with passages which would fit this kind of equipment. We had to sell the house we had, and we...”</td>
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| Actions until an effective strategy/solution is identified to the evolving caregiving situation | Accommodate CR needs (i.e. moving or renovating house) | Bought a house which had extra-wide entrances, and extra-wide rooms, to accommodate him.  
CR: “…he (CG) was orchestrating a variety of renovation projects here at the house. Like I said, it’s an older farmhouse, so ramps were required, I needed a new front door 36 inch wide, so that was constructed for us as well a ramp inside the house. We have got a sunken living room level, so ramps were installed from the front entrance into the living room. And then we had the bathroom completely renovated as well. We had a roll-in shower, walk-in shower installed, as well as the toilet was made to accommodate the commode, and an accessible sink that I could wheel under. So, Name-X (CG) was busy orchestrating all that, so by the time I was discharged that was all ready for me. When we arrived home it was really a smooth transition. Everything was in place.” |
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<td>Learning from mistakes (trial and error)</td>
<td>CR: “Well, we didn’t really, that’s why it got bad fast. She (CG) just pretty much thought it was a little pimple or something there, it was just a little red mark, and then after I was up on it for a couple days it was the size of a dime and starting to wear in so that’s when we called Extra-Mural, but by then it was spreading so fast. Within a couple of months even of staying off of it, it wasn’t getting any better… now every time we do a catheter she’s checking my butt, make sure there’s no little red mark even.”</td>
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<td>Finding alternative caregiving methods:  - when original method no longer works  - to identify best caregiving method for different situation/scenario  - to make caregiving efficient/easier)</td>
<td>CR: “I think the thing that she’s (CG) learned most, well, the hard way, really, when she’s doing catheters, my bed, it’s down quite low, so she was bending over and not bending her knees and it was really, really bothering her back so we ended up getting a bed that will rise up when we’re doing anything like that. But, no, pretty much everything that happens, you can come up with a solution.”  - In the context of finding a better way to do catheterization when original method no longer works</td>
<td>CR: “Skills are (finding) the easiest possible way to move me without my legs kicking and going, and how to get me in and out of the bathtub, how to get me dressed and things like that, we learned the easiest possible way.”</td>
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|   | - In the context of finding the easiest/most efficient way to transfer (in reference to CG)  
   |  
   | CG: “I clean his urine out every three hours if I don’t have an indwelling. I only put an indwelling and that stays in all the time mostly on weekends so that I can sleep at night and I can go out and do my groceries and whatever because somebody from the family can be here and just empty the bag. Usually during the week I do the intermittent catheter from Monday to Friday.”  
   | - In the context of finding the best catheterization method (indwelling vs. intermittent) for different situations  
   |   |   |
|   | - Trying multiple strategies until solution is found to caregiving problems  
   | CR: "We’ve (CG) tried the pressure mapping and everything for different cushions and I have the best cushion for whatever the pressure map shows.”  
   |   |   |
|   | - Using creativity in problem-solving/caregiving task  
   | CG: “You’re used to living a certain lifestyle before something like this happens and there are some foods you don’t know. He (CR) doesn’t like them. I try and make smoothies with juices. I’m working on trying to give him some smoothies. I just have to be very flexible because people get sick of eating the same thing all the time. Even we do, everyone does so you have...I’ve tried to be aware of that. I think the food management is a difficult thing, but I just keep working away at it.”  
   | - In the context of nutrition management  
   |   |   |
|   | - In the context of getting CR through bowel management  
   | CG: “I’ll say to him (CR) hand me some toilet paper or flush the toilet. I feel like sometimes I’m playing a game with him just to distract him. I don’t need him to flush at that moment. I don’t need him to hand me toilet paper. I don’t need to point out something that’s on the wall just so that he can look over there for a second, but I’ll do it because it makes it simple. Or I’ll start a conversation as I’m doing it just so that maybe he’ll talk about something different so that he can get it done.”  
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<td>Time management</td>
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<tr>
<td>Timing daily activities according to CR’s needs/rhythm (related to injury condition)</td>
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<tr>
<td>Navigating the Healthcare &amp; Social Services System</td>
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|  | Actively seeking resources/information:  
- Resources: to provide care to CR (i.e. effective assistive devices)  
- Information: to learn/continuously update caregiving techniques (i.e. direct advice/training or making careful observations of care techniques others use) |  |
|  |  | CG: “We tried so many cushions and so many wheelchairs for Name-X (CR) and we still couldn’t get one, the proper one, to take away the pressure, all the pressure points. I mean we tried every make and model they had before we finally found one that was fairly suitable.”  
- In the context of actively seeking appropriate wheelchair (resource)  
  - CR: “He [CG] really took initiative. He worked with the occupational therapist at Lyndhurst who was a wealth of information, gave us different measurements for different heights, where the sink should be, the width of the commode, where we needed to install the toilet to get the commode over. So, he worked closely with her as well as doing a lot of research online.”  
  - In the context of actively seeking advice/information on home modifications |
|  |  | CG: “Every time I went there there’s different nurses. They all have different styles, different ways of doing things. I got a broad perspective of all that because everyone has a different take on things, you know how that is. I feel I was really schooled on the catheterization and those things because that’s what I was really worried about the most so I asked everybody. Why are you doing that, how are you doing that, etcetera?... just watched and I asked a lot of questions when they (nurses) came in to take care of Name-X (CR).”  
  - In the context of actively seeking information on catheterization techniques by making careful observations of how nurses provided care at the rehab |
|  | Assessing care received in the healthcare system |  |
|  |  | CG: “If she (CR) wants to learn it, if anyone wants to learn to do it themselves their way, do it, especially when they had already ... and then, they were putting her back further. I mean she was getting frustrated and I was getting frustrated. So, at the end of it, I took her out. I said, this is foolishness.” |
In the context of assessing the self-management technique provided to the CR, which was rather general and not tailored

| Seeking medical assistance from healthcare professionals in a timely manner | CR: “I can’t feel my legs down there, I was just kind of like, oh, okay, it’s bleeding, but it doesn’t hurt, so it must be okay. But of course it doesn’t hurt if you don’t feel your legs. I just went to him (CG) and said, kind of lifted up my leg and said, does this look bad, is it okay if I just put a band-aid on. He’s like, no, no, we need to go to a hospital, your bone is sticking out. It’s like, oh, is it, he’s like, yeah. He’s just like, don’t even move it or whatever, and just packed me up in the car, and then took me to Emergency.” |
| --- |

| Seeking supportive care (trained third party caregivers, such as PSWs - not informal networks, such as family/friends) | CG: “I was working, and how he was going to be supported in the house. But thankfully, we had home care that we set up, and that took a lot of pressure off that way.”
CR: “Well, they were older so it’s not like they were young kids. When I got injured, I was 30. My parents worked, and they weren’t young so stuff that hindered was they were busy during the day so how can they help? So, we had to hire a private attendant to help me out. It worked out to be the best way. Their age and working hindered them helping me. They weren’t young, and I didn’t want them to help me.” |
| --- |

| Providing training to third party CGs: formal/informal | CG: “I found that as we started getting PSWs in and support for Name-X (CR), I’m still the person that trains them. They sometimes come in not knowing what to do...because there are certain things that certain agencies don’t allow their PSWs to do, so I fill in those gaps.”

CG: “My sister, when she used to give me a break once in a while, I just showed her how to do it (catherization).” |
| --- |

| Providing for Psychosocial Needs | Skills related to providing care in a holistic way and Maintaining a sense of humour or spirituality | CG: “When he (CR) becomes sad I pray from my God that he doesn’t become sad, and I want to make him happy. I make some special thing for food. I try to make...” |
ensuring the psychological, social, and spiritual needs of the CR are recognized and addressed accordingly

Providing care with dignity:
- Ensuring privacy (i.e. respecting CR’s personal space)
- Respecting CR’s decisions (i.e. enable CR to make choices about the way he/she wants to be cared for)
- Empowering CR’s autonomy (i.e. enabling CR to maintain independence while providing needed assistance)
- Ensuring privacy/dignity during personal care (i.e. closing washroom door during bladder care)

CR: “I think I’ve seen it in others, in other quads that I’ve known, where people forget that they are dealing with adults that want to make their own decisions, that want to have some degree of privacy, as much as they can have it.” – in reference to his wife, CG

CG: “She (CR) is strong. They (HC providers) wanted to put that stupid cuff on her to put in a fork, spoon, knife, whatever. She refused that. She said if she couldn’t learn to way the proper way, then she wasn’t going to eat. So, I just put it in her fingers at first, lifted it through, and she learned to get it up there herself and now she can pick it up herself and do it.”

Providing positive coping strategies:
- Distraction
- Time away
- Entertainment
- Relaxation techniques

CG: “I just play his (CR) music. He loves sports so I have a TV, I have all the sports channels. He likes that. I’m in the process of ... I want to get him some audio books to listen to. I know the library has them. I haven’t done that yet, but he has one of those iPhones that you can, you know, get an audio book. So I’m working on that...When he gets fed up I’ll say well let’s go out and I’ll put in the van. We might go down to Vaughan Mills just to get change of (atmosphere)... then he goes to therapy.”

CG: “But the main thing what we wanted Name-X (CR) to see is that there is life, even the way he was, so this is why we spent a little fortune building him a studio, that he would be able somehow to live as normal life as possible. Though there was no really income from it, but this was not important to us. What’s important to us was the activity itself.”

Guiding with patience

CG: “In the first place, I do have all kinds of patience. I know he’s (CR) going to forget, and I expect it, so I just go along with it. If he says, oh, I forgot again, I say, well, that’s okay. No problem, that’s alright, we’ll just carry on with it now, or do it now, or whatever. Like if
he’s supposed to go on an appointment somewhere, and I call and say are you ready for the appointment today? And he said what appointment? And then I’ll tell him. And, oh, I forgot. I say that’s okay, don’t worry about it. Just get ready and go, because I’ll be checking with you and make sure you have gone. And he says, okay, fine, thank you for calling. I appreciate that. So, this is it, is to be relaxed, have the patience...”

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<th>Ensuring social interaction/integration:</th>
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<tbody>
<tr>
<td>- Interaction with family/friends</td>
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<td>- Involvement in parasports/activities</td>
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<td>- Involvement in community (peer support groups)</td>
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CG: “I suggest we go out, change the atmosphere. He (CR) has a couple of nice friends that still come. He went to, his buddy took, he went down to the Blue Jay game and he was in there in one of those booths and he was out. Then we all went down to another Blue Jay game. He went to a hockey game a couple of times. I mean just things that he likes. He’s not really open to socializing with other quadriplegics unfortunately because he could see they would have something in common, but he’s not interested...”

CG: “Well, she (CR) found a place which does adapted kayaking. She’s on the water and does her paddling that way. We purchased an adapted bicycle, which kind of clasps onto her wheelchair and it’s one of these bikes which is hand-driven...So, we’re doing it still in many ways in a perhaps slightly more curtailed circumstance, but she’s doing it...So, we’re doing it now, admittedly with a bit of research.”
## Codes for Impact of SCI on Relationship:

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<th>Theme</th>
<th>Code</th>
<th>Description</th>
<th>Example</th>
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| Deterioration of the Relationship | Protective Behaviours | Process of safeguarding the other person’s (CR or CG) emotional or physical wellbeing resulting in negative consequences | e.g. protective buffering  
- hiding worries/concerns, and yielding to the other person in an effort to reduce the other person’s upset and burden (e.g. CR hiding symptoms from CG to reduce burden, CG hiding burnout from CR)  
  e.g. over-protection  
- particularly the CG underestimating the CR’s abilities and assume responsibility for everything, diminishing the CR’s feeling of self-efficacy and autonomy (and increasing workload for CG)  
CR: “Just because one of the things, when you become a quad or someone in my condition, is that you rapidly lose all complete sense of privacy at all. So, there are things that I will discuss with a caregiver that I don’t particularly want Name-X (wife) to weigh in on. She’ll get pissed off if she finds out, three weeks later, that I’ve made a decision without telling her. So, I don’t want to argue with her. I don’t want her opinion. I don’t need her opinion. I’m not her child, I’m her husband. So, the relationship is difficult, the fact that you lose all privacy is a difficult thing. And if I get a caregiver that respects that privacy, then sometimes she will turn on that person, sort of passive-aggressive type of, and drive them out of the picture so you’ve got to hire somebody else.”  
CR: “I made it look like, you know what, I’m totally okay, don’t worry about me, everything is fine. I almost never wanted to complain about anything to him (CG), thinking, oh my god, this is too much already, and if I even tell him that, oh my god, my hands hurt today or something, and I can’t do something, I’m just putting more pressure on a person. I usually would never ... I would just kind of deal with the pain, and move on because I didn’t want to put any more burden on that person...I think he got frustrated with me a lot, not telling him what was wrong or something. I think there was a lot of frustration on his part, on knowing what to do or how to help because I wasn’t co-operating, and letting him know what kind of help I needed.”  
CR: “Eventually, every time I had nerve pain it was like torture for my family so I would lock myself in a room because I didn’t want anyone to see me and what I was going through.”  
CG: “I found the hardest was, anytime I’d go anywhere with him, I’d see that he was struggling a little bit because it was a little bit uphill or whatever. And I would put my hands on the wheelchair to help push him, and he’d get mad at me. He said, mom, I am doing it on my own, just don’t touch it. And I kept doing that right at the start, and now I know, I don’t touch him unless he asks for help, or I’ll say to him can I help you a little bit? And then he’ll say, yeah, okay. But no, he doesn’t like to do that, he wants to do it on his own.” |
Asymmetrical Dependency

Either or both individuals in dyad lean heavily on the other person/one another (to meet their physical/psychological needs) that either/both of them lose their identities (CG progressively taking on caregiver identity over spouse identity) or self-efficacy/autonomy is diminished (CR becoming less independent)

e.g. CR relying too heavily on or has higher expectations of CG to meet nearly all of their needs;

e.g. CG enabling, where he/she does for CR what that person should be doing for him/herself, allowing (enabling) the CR to continue the inappropriate behaviour

- sense of obligation/duty (particularly parent/child relationships)

- CG feeling the need to be needed

CG: “He (CR) want to occupy (exploit) me. He wants to occupy me, and what he can do himself, he wants me to do it, yeah. But after, in 2006, I exhausted. I told him that I will not be with him, and then I went back home (to parents’ house).”

CR: “When you’re in a wheelchair, people will do everything for you, if you let them. Some people who are injured are more than happy to take advantage of that. Especially parents. I’ve noticed this over the years. It’s really hard for a parent to see their child in that situation. Anybody who sees their loved one struggling, they have a really hard time with that and they want to help them out as much as possible, which means they want to do things for them... We’re so focused on the injured individual that we don’t realize what the caregivers are going through. Again, they’re questioning, am I pushing too hard? Should I back off? He’s frustrated, should I take over or should I let him work through that? All of that creates all kinds of anxiety and that anxiety day over day really starts to wear on a person. By the time the person, the caregiver, realizes it, they’re relationship with that individual is probably affected in a negative way.”

CG: “He was imposing me. No, you have to do. He was also so upset, and I was also upset. We don’t know how to deal with it, and also for many years I didn’t go back to meet my parents. After his accident, I didn’t go. Maybe from 1999 to 2006, I didn’t go to meet with my parents. When I said that I wanted to meet with my parents, he started upset, and he thinks that I am but he’s sick.”

CG: “Yeah, I think probably that’s the mother in me, right? I want to make his life as easy as I can, and so I do whatever. But yeah, it’s a responsibility, obviously, but I don’t mind doing it either. Again, I have always done the cooking and the house. That’s not something that my husband ever did or Name-X (CR) probably never... It’s not to say that he can’t do it, because he did live on his own while he was in school or whatever. So, yeah, I guess I’ve just accepted that that’s my job in the house, and the same with laundry and that sort of thing, and the housecleaning. That’s never been big on either my husband’s or Name-X’s list, because I’ve always done it. And I guess because of my generation, that’s the way I was raised and so it’s just a given in this house.”
| Difficulty Adapting | e.g. emotionally: negative emotional coping  
e.g. physically: social isolation (due to physical restrictions) | CR: “I think we really didn’t adjust to it, we just kind of went around it. We just kind of tried to do everything we did before. I got injured, and tried to avoid the subject as much as possible, it felt like. We never … there was always that big elephant in the room, but nobody really wanted to talk about it because nobody wanted … I didn’t want my feelings to hurt, and I didn’t want his feelings to get hurt. It was always, you almost never wanted to accept that you were going to be in … even ten years later, you’re still like, well, no … 15 years later, no, no, I’m still going to walk, that magic pill is going to be |
|---|---|---|
| Loss of Sex and Intimacy | e.g. loss of spontaneity  
e.g. role change (from spouse to caregiver) | CR: “I think you just get into a cycle, very repetitive, that you don’t even ask anymore, you just kind of get used to the way things are done, and then you just repeat them every single day, so it’s just kind of forgotten. I think that’s a lot what broke us apart, it was just, he started doing his own stuff, that I wasn’t able to do, and I was left alone a lot. I thought, well, why bother staying...Again, there was no being spontaneous if you felt in the mood or whatever, it was very calculated, okay, well, it’s going to happen. I guess I could not be spontaneous, so everything was mapped out. That it’s almost like, I don’t know even if it’s worth it anymore. It’s just like, same thing over and over, there is no variations to it, I’m going to say.”  
CR: “As much as she gives me care she is more upset, so it’s more difficult and bonding is more loose.”  
CG: “I think he’s more sad because he had let’s say an average 20-year-old sex life, no issues, and then his accident happened. But he’s one of the lucky ones that it still worked. And then this new bladder infection, yeah, so he’s very sad. But I think he’s sad for me, for him and for me. But I’m not sad for me because for me it’s like, we wanted a baby. I don’t know if we would have gotten one anyway with the way that he was sexually. Like he wasn’t ejaculating, so we would have had to find a way. Then he stopped being able to. It is what it is. I’m okay with it. He’s sad about it, but he’s sad for me too. And I wish he wasn’t. But for me it’s not a big deal. There are so many other ways.” |
available. It was just never accepted that I would be in the chair for the rest of my life, so it was almost like, never addressed… I definitely would have never wanted to give up on the idea that I will walk again, I want it. But I wanted to maybe to say, well, for right now, until that happens, we (CG) have to find new ways and new things of doing stuff, while we’re waiting for that transition.”

CR: “You go through all of the … it’s almost like the stages of grief. And ultimately, there’s acceptance, but there’s certainly a certain amount of underlying anger that’s still there. This isn’t the retirement she (CG) planned on, and so a lot of the stuff that we had planned to do during our retirement we’re unable to do, so there’s that. We’ve been married for 50 years, so you learn to adapt to the needs of the other person. Emotionally, she’s still involved in looking out for me and trying to make sure that I do the right thing for myself, and that I just do the right things for me. Sometimes I resent that…that she thinks that there are things that she needs to do that she doesn’t need to do. One of the things that you have to keep reminding people of is that you’re not sick, not stupid and that you’re not mentally impaired. There’s a certain amount of friction there develops…Hopefully, she would get to the point where she could deal with the injury. It would make her life much more comfortable. Frankly, I’m not worried about it for me. I worry about it for her. You don’t stay married for 50 years by trying to change the other person. You adapt to what they have and what they haven’t. She feels trapped at this point. So be it.”

CR: “Definitely our time out was limited because I felt like he shouldn’t be doing that, that’s probably hard on him, the weight of a chair, the weight of me, and stuff. The going out time was definitely limited.”

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<th>Maintaining/ Re-Building the Relationship</th>
<th>Interdependence</th>
<th>Both individuals within dyad have equality and balance in how each individual’s needs are met, while being able to maintain their own</th>
<th>e.g. shared activities/roles e.g. empowering personal autonomy/maintaining individual identity - knowing when to step</th>
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<td>CR: “I do a little bit of laundry, like I put the stuff in the washer and transfer it to the dryer, but she folds the clothes because I really hate folding clothes. If she has a faucet leak, then I’ll fix that, so there’s stuff like that. So, we trade back and forth that way.”</td>
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<td>CR: “If I can’t do something I’ll keep trying, and trying, and trying. But, no, she’s really encouraging. She’s like, well, you know, try it this way, if that doesn’t work we’ll try something else, if not, I’m here, I can do things. No, she’s really good but I like to do as much as I can. If I can’t do something I’ll...”</td>
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<td>Shifting Commonalities</td>
<td>The process of changing focus of common interests to adapt to the new situation post-injury</td>
<td>e.g. enhancing intimacy through a change of focus on shared activities, rather than focusing on the loss of sex e.g. focusing on CR’s abilities and interests, rather than the loss of function/prior life</td>
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<td>CG:</td>
<td>“I think you just have to re-shift it to commonalities of things that you enjoy to do together, such as watching movies, and baseball. Re-shifting to commonalities in other areas.”</td>
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<td>CG:</td>
<td>“And one way of doing that is...he loves to watch movies, so I generally encourage him to watch comedies and things like that, something he’s going to get a laugh out of, more so than something that is sad and can make a person depressed. That’s worse. So, we go the other way, and give him happiness and not depression...He loves music, he plays the guitar really good. And that’s sometimes what I do too, when he comes to my place. He has his guitar here, so I’ll get it out and say how about singing me some music? And he’ll say, okay. And sometimes he writes songs and whatnot too, and I sit and I listen to them and the whole bit, so it’s things like that.”</td>
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| Tasks in order to engage with the CR intimately and/or cope with the burden of caregiving | Trying to give an example of how you can incorporate some of the caregiving into a more intimate act... At the same time, she’s caregiving, but it kind of changes to more of a romantic experience. I’m not saying this works for everybody, I’m just saying, keep an open mind, because by doing that you’re reducing the caregiving aspect of it and it’s more of a different way of being intimate... The way I’m talking to you, the ideas that I’m talking about now, about using caregiving in intimacy, that was not talked about in rehab at all. This is stuff that I’ve learned through the years. I think in the beginning, something like that, just giving a couple that idea that your caregiving doesn’t necessarily mean that it’s a medical environment. It might take like a year before you can get into this kind of thinking, like this isn’t probably something you’d do the first time, but just to have it out there that this is a way we can lessen the caregiving role and add to the more intimacy."
| Creating a New Normal | Progressively adapting to the new life post-injury by returning back to the way life was before the injury e.g. taking up previous shared activities/interest e.g. returning to work (aim for a balance in being household provider) e.g. working together towards realistic recovery expectations & accommodating (patience and mutual understanding) CG: “...we carried on accordingly. I mean we had to, of course, learn a lot of new aspects in terms of making life acceptable and comfortable as much as possible. So, I think we did kind of a dip in the graph, but we pulled ourselves up again to a level of normality. Of course, it would have been so much easier for Wife-X to be in good health and we would have done what many of our friends do. But we do it still, in brackets. They travel all over the world. So, do we, except we always have to put the caveat in, well, is it adapted, what are the possibilities of doing a, b, and c. Which when people, for example, go on a cruise, they can book an excursion to Machu Picchu or something, we can’t. Things like that. Those are little things which curtail our mobility, but nevertheless we’re doing it anyway and we look forward to that. I think that allows both of us to not miss out shall we say. It would have to be recalibrated and adapted, but we’re doing it anyway. And that I think is something that is very bonding and very uplifting for both of us.” CG: “...he says, mom, I am not going to be on this the rest of my life. I can work. Yes, even if I’m in a wheelchair the rest of my life, I am not going to be on government assistance for the rest of my life. If I have to do a desk job, which was not his ideal job...like I say, he wanted to be a police officer and be out doing things. But if that doesn’t work out, he said I’m going to have a job. So, right now, his focus is to walk again. But I think as soon as that... hopefully that happens, and then he will be looking for a job.” |