AN INVESTIGATION OF THE JOURNEY OF CARE RELATED TO SECONDARY HEALTH CONDITIONS FOR COMMUNITY-DWELLING PERSONS WITH SPINAL CORD INJURY

by

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A thesis submitted in conformity with the requirements for the degree of Doctoral of Philosophy
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This thesis comprises an in-depth analysis of the journey of care in managing secondary health conditions (SHCs) for community dwelling persons with a spinal cord injury (SCI) in Ontario. Persons with SCI are at high risk of preventable secondary health conditions. The Network Episode Model was used to help conceptually guide the thesis. To determine whether potentially preventable SHCs may be related to emergency department (ED) use, in the first study, I examined patterns of emergency department use (ED) such as the number of visits by year post injury and characteristics of these visits (e.g., acuity level, timing of visits, reasons for visits). Results from this study suggest that the ED is being used as an inappropriate substitute for primary health care for individuals with traumatic SCI. In the second study, to better understand care provision in the community, I examined the caregiving networks, in particular the structure
and roles of informal care. While networks are smaller for persons with SCI compared to the general population, these ties are strong, which is essential when the roles involve a level of trust and flexibility. These informal networks serve as critical key players and secondary team members. Finally, in the third study, the journey of care related to SHCs was examined at the micro (individual level), meso (care provider level) and macro (health system level). Significant challenges at the macro health system level were identified such as rigid policies, wait-times for services, funding and social inequities. These analyses have led to a better understanding of the journey of care, which seems to be a challenging and an uphill struggle for persons with SCI, care providers, and community-based advocates. If we are to make significant gains in minimizing the incidence and severity of SHCs, we need to tailor efforts at the health system.
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Chapter 1: INTRODUCTION

The purpose of this chapter is to:

1) Describe the epidemiology and clinical characteristics of Ontarians with spinal cord injury (SCI)

2) Highlight the importance of secondary health conditions (SHCs) and their impact on health service utilization and quality of life

4) Describe the challenges with care coordination and the importance of caregiving networks

5) Introduce the primary thesis questions

Epidemiology and clinical characteristics of spinal cord injury

Traumatic SCI

A spinal cord injury (SCI) is a chronic condition that involves an insult to the spinal cord resulting in significant motor, sensory and/or autonomic impairments. In Canada, there are approximately 44,000 individuals currently living with traumatic SCI (TSCI)\(^1\) and approximately 1100 new cases per year.\(^2,3\) Higher incidence and prevalence rates are reported in the United States with 12,400 new cases per year and an estimated 259,000 prevalent cases.\(^4,5\) The age-adjusted incidence of traumatic SCI in Ontario is approximately 23.1 per million (95% CI: 20.2-26.3).\(^3\) The distribution is bimodal with peaks at the third and eight decade.\(^2\) A recent Ontario population-based study identified the mean age of injury to be 51 years which is slightly higher than previously reported.\(^3\) This higher mean age could reflect a shift in the aging population with increasing falls amongst the elderly.\(^2,3\)

The primary causes for TSCI in Ontario are falls (41%-50%) and motor vehicle collisions (25%-38%).\(^3\) Other mechanisms of injury include being hit by an object, or sustaining an injury
due to a firearm-related event or sports-related event. While males are more likely to have a TSCI compared to females (3:1 ratio), females are equally as likely to have an injury secondary to a fall. Further, the female to male ratio decreases with increasing age. Advances in roadside management, early acute medical therapy and surgical decompression, and in rehabilitation care have contributed to increased life expectancy and frequency of community discharge with the mean survival time reported to be more than 30 years.

**Non-Traumatic SCI (NTSCI)**

To date, the majority of literature on SCI characterizing the incidence, impairments, demographics, and health care utilization has largely focused on people with traumatic SCI (TSCI), with minimal research related to the non-traumatic SCI (NTSCI) population. NTSCIs are caused by a variety of medical conditions including but not limited to: vertebral spondylosis, tumor compression, vascular ischemia, infectious abscess, and transverse myelitis. Given that the diagnosis of NTSCI is typically progressive and largely dependent on diagnostic availability and skills, it is difficult to determine specific incidence rates as cases can be missed. The incidence of NTSCI is not known due to the lack of international consensus on the identification and characterization of NTSCI. The International Spinal Cord Society (ISCOS) with the World Health Organization has an international working group to address this issue using International Classification of Diseases (ICD-10) codes; however, they have yet to be adopted as an international standard, unlike the International Standards for Neurological and Functional Classification of SCI (i.e., American Spinal Injury Association Impairment Scale (ASIA) exam). Ones et al. suggest that NTSCI accounts for approximately one third of all SCI cases admitted to inpatient rehabilitation; however, with the rising incidence of cancer related SCI
and the aging population, others suggest that NTSCI represents at least 50% of all inpatient rehabilitation SCI cases.7

The demographics of the NTSCI population have been previously reported to differ from TSCI: they are generally older, retired, paraplegic, and have more co-morbidities.11,12 Further, the prevalence of NTSCI is relatively similar amongst males and females.11,12

**Type of Injury**

The International Standards for Neurological and Functional Classification of SCI is widely used and categorizes the neurologic level of injury as either tetraplegia or paraplegia.13,14 An injury sustained between the first and eight cervical segments denotes tetraplegia classification and results in motor dysfunction for all four extremities. Paraplegia is defined by an injury occurring below the eight cervical segment.

Neurological status (i.e., preservation of motor strength and sensory function below the level of injury) can be further classified using the American Spinal Injury Association (ASIA) Impairment Scale.14 The ASIA impairment scale has the following five (A to E) sub-categories: (A): complete- no sensory or motor function is preserved in sacral segments S4-S5; (B) incomplete- sensory function is preserved but there is no motor function below the neurological level of injury; (C) incomplete- motor function is preserved below the neurological level of injury but muscle strength is less than grade 3 (less than anti-gravity); (D) incomplete-motor function is preserved, and muscle strength below neurological level is greater than or equal to grade 3; and (E) normal-there are no impairments in sensory and/or motor function.

**Functional Improvement and Rehabilitation**

In Ontario, approximately 50% of patients admitted to acute care for the incident TSCI injury are discharged to inpatient rehabilitation.15 The length of stay (LOS) in acute care widely
varies depending on the type of injury and comorbidities. For example, during 2000 to 2004, the median LOS for complete tetraplegia was 101 days (n=196) compared to 64 days (n=398) for incomplete tetraplegia, 67 days for complete paraplegia (n=291), and 49 days for incomplete paraplegia (n=271). In our recent study, we identified a median inpatient rehabilitation LOS of 59 days (31-101) and 36 days (18-64) for TSCI and NTSCI, respectively. With the exception of persons with complete tetraplegia, the majority of individuals with TSCI are ultimately discharged to home (approximately 80%) and 10% to acute care or a long term care facility.

**Secondary health conditions (SHCs) and implications**

SCI and associated multi-system impairments often leads to the development of serious secondary health conditions (SHCs). Recent research suggests that SHCs in community dwelling individuals with SCI are associated with a high number of physician visits, hospital readmissions, and morbidity.

SHCs can include the following: respiratory disease, urinary tract infections (UTIs), heart disease, osteoporosis, overuse upper extremity injuries, sleep disorders, sexual disorders, suicides, pressure ulcers, chronic pain, fatigue, depression and/or respiratory infection. Individuals with complete injuries are more likely to have chronic problems with genitourinary and respiratory function. Respiratory complications (e.g., pneumonia) are more common amongst individuals with tetraplegia and pressure ulcers are more prevalent amongst those with paraplegia. Severe chronic pain occurs in approximately one third of the SCI population. Pain, weakness, and fatigue have been shown to be associated with social and mental health impairments. Respiratory disease, urinary tract infections, heart disease, and skin infections are purported to be more prevalent in the TSCI population compared to NTSCI; however, Ones
and colleagues suggest that the frequency and type of complications after SCI are similar amongst these two sub-groups in the inpatient rehabilitation setting.\textsuperscript{11}

Unfortunately, there is no clear consensus on a definition for SHCs, as there is significant diversity in how SHCs are operationalized and measured.\textsuperscript{31} As noted in a recent review by Jensen and colleagues, this lack of consistency is not assisting in moving the research agenda forward to assist with the prevention and reduction of SHCs.\textsuperscript{31} For instance, the Institute of Medicine (IOM) has defined SHCs as any mental health or physical condition resulting from a primary disabling condition,\textsuperscript{32} but other definitions have included more broader social and activity limitations.\textsuperscript{33} For the purposes of this literature review and thesis, the definition of SHCs is limited to physical and mental health, as recommended by both the IOM \textsuperscript{32} and the recent review by Jensen and colleagues.\textsuperscript{31}

SHCs can develop either through direct or indirect mechanisms related to the SCI.\textsuperscript{31} For example, a SHC may develop directly from the impairment (e.g., autonomic dysreflexia, spasticity) or indirectly due to factors related to the impairment (e.g., urinary tract infections that may result from dependence on catheters due to bladder emptying challenges).\textsuperscript{31} These SHCs can contribute to “accelerated aging” for persons with a SCI, as individuals with a SCI are at a greater risk of developing age-related chronic conditions (e.g. hypertension) at a younger age compared to persons without a disability.\textsuperscript{34} Additionally, aging has been associated with increased number of SHCs\textsuperscript{22} (e.g., bowel complications\textsuperscript{35}, urinary tract infections\textsuperscript{36}).
Utilization of Health Care and Costs

Despite the fact that many of these SHCs are potentially preventable, they are purported to be key contributors for re-hospitalizations and/or death in the post-acute phase.\textsuperscript{20,24} The initial transition period, typically within 18 months of injury, has been suggested to be a critical phase in the development of SHCs and increases the likelihood of the individual’s interactions with the healthcare system.\textsuperscript{37,38} In the US, the average rehospitalization rate within the first year of injury was 55\% decreasing to 37\% after five years.\textsuperscript{38} Similarly, the rates of ED and physician visits in Canada are high in this same time period.\textsuperscript{17,23,24} More than 50\% of individuals with SCI self-reported having problems with spasticity, pain, and bladder infections in the year following injury, and for several SHCs including pressure ulcers and autonomic dysreflexia, the odds of developing these SHCs increased per year post injury.\textsuperscript{22} Thus, while this transition period is particularly vulnerable, these complications remain to be chronically problematic in approximately 20\% of this population.\textsuperscript{27}

The direct and indirect costs associated with a SCI are substantial, with significant financial burden placed on the individual and his/her family, the health care system and overall society.\textsuperscript{39} In Ontario, SCI costs the government over $1.38 billion per year.\textsuperscript{39} A recent Canadian report has estimated that the direct (e.g., health care, attendant care, equipment and home/vehicle modifications) and indirect costs (e.g., loss of employment morbidity, and unpaid caregiving), the total lifetime cost per individual with traumatic SCI in Canada is estimated at $1.6 million for paraplegia and $3.0 million for tetraplegia.\textsuperscript{39} Similar results have been reported by researchers in the United States (US), with lifetime direct costs ranging from 2.1 million (United States Dollars, USD) to 5 million (USD) depending on the severity of injury.\textsuperscript{40}
The initial inpatient acute care and rehabilitation direct costs are significant.\textsuperscript{39,41-43} Recently, DeVivo and colleagues identified the mean initial acute care costs of $76,711 (United States Dollars, USD) and mean rehabilitation costs of $68,543 (USD).\textsuperscript{43} In Alberta, direct health care costs after traumatic SCI in the first year following injury were determined to be $121,600 (Canadian Dollars, CND) per person with a complete SCI, and $42,100 (CND) per person with an incomplete SCI. In the subsequent five years following injury, annual direct costs were $5,400 and $2,800 for persons with complete and incomplete SCI, respectively.\textsuperscript{42} Similar high costs have been identified in Ontario, with mean direct health costs of $100,476 in the first year following traumatic SCI.\textsuperscript{44}

SHCs are key contributors to health care costs.\textsuperscript{41} Recently, DeVivo and colleagues identified that urinary tract infections were the main cause of unplanned hospitalizations for persons with either tetraplegia or paraplegia living in the community.\textsuperscript{41} The mean costs per hospitalization associated with these urinary tract infections were $12,617 (USD). The second most common cause of hospitalizations for persons with tetraplegia and paraplegia were respiratory complications and skin conditions (e.g., pressure sores), respectively. Costs associated with skin conditions were the most significant, with a mean cost of $38,866 per hospitalization.\textsuperscript{41} It has been estimated that by reducing the number of unplanned hospital readmissions for SHCs by only 10% could result in a reduction of $66 million (CND) by the health care system in Canada.\textsuperscript{39}

\textit{Community Environment}

The majority of individuals with SCI are discharged to the community given the advances in acute care management, rehabilitation, assistive devices, and the increasing focus on
home/community care. Only 2% of TSCI patients are discharged from acute care to long-term care and less than 20% are discharged from rehabilitation to long-term care. Previous research has suggested that there are several barriers that influence health care delivery and use for this population once discharged to the community. Structural barriers relate to the access (i.e., inaccessibility of office facilities) and availability (i.e., absence of services) of services; whereas process barriers are obstacles which an individual may encounter with the health service delivery process such as inadequate services, and fragmentation of services for example caused by information and knowledge gaps; client and provider attributes such as self-efficacy.

**Impact of SCI on quality of life**

Despite the majority of individuals being discharged to the community, following a SCI, only 10% return to the workforce. SCI significantly impacts the body as well as conceptions of one’s self. Often this devastating injury results in dramatic changes to an individual’s entire physical, economic and psycho-social environment. Several key concepts that significantly influence life satisfaction following a SCI can include issues related to an impaired body, sense of loss, changes in relationships and social roles (with the individual and his/her family, friends), decrease in self-determination and agency, changes and/or loss of occupation and self-worth. The chronic risk of developing SHCs further threatens life satisfaction and quality of life.

**Integration of care and caregiving networks**

The high utilization rates of health care services suggest that care needs in the community are not being met for this population. Given the reduced lengths of inpatient rehabilitation stay, persons with SCI often require outpatient community services to manage SHCs that have not stabilized at the time of index discharge. This shift from inpatient care to
community has led to an increased role of formal care provision (paid medical professionals) as well as informal caregiving (unpaid providers such as family, friends, and community organizations).54

Coinciding with this shift over the past 20 years, there have been dramatic changes in population demographics with an increasing prevalence of an aging population with chronic disease.55-57 These combined factors have posed challenges for integrating health services along the continuum of care. Given that improved integration of care contributes to better quality, cost-efficiency and overall health care performance,58 there is widespread interest in optimizing care coordination especially for persons with chronic conditions, such as those with SCI.59

Integration of Care
Integration of care has been associated with numerous terms such as “transmural care”, “continuous care”, “seamless care”, integrated care pathways”, and “integrated delivery networks”.59 The World Health Organization defines integration of care as “a concept bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation, and health promotion. Integration is a means to improve the services in relation to access, quality, user satisfaction and efficiency”(p.7).59 Despite efforts to improve quality, efficiency, and cost-effectiveness,60 poor integration of care still remains problematic.61-66

Community Networks of Care
Community networks of care are important contributors to appropriate and integrated health care delivery.60,64,67,68 The shift from centralized to regionalized care has increased the burden on patients and their informal care networks, especially for those who are most vulnerable to navigating the health care system.64,69 With increasing demands placed on
informal care providers, these informal interactions may contribute significantly to overall health outcomes, as coordination often occurs through informal interactions rather than *solely* by formal networks.\textsuperscript{60,68,70-73}

Understanding integration of care is not an easy task, as the concept of care provision itself is multi-faceted and reflects complex social relationships.\textsuperscript{74} Further, formal and informal caregiving are often complementary and interdependent.\textsuperscript{74} Formal care-providers are usually provided by paid medically-trained professionals such as physicians, physical therapists, occupational therapists, nurses, speech language pathologists, social workers, psychologists, and personal attendants. Informal care-providers are typically unpaid individuals with minimal previous formal training in health care.\textsuperscript{74} In contrast to formal providers, informal care providers typically have a pre-existing relationship with the individual for whom the care is being provided. Informal care can involve tasks such as management (organization, referrals), advocacy of care, assistance with cooking, shopping, cleaning, household maintenance, mobility, community participation, basic daily grooming, advice and emotional support.\textsuperscript{74}

### Guiding conceptual frameworks

**Andersen behavioural model for health care utilization**

A significant challenge in understanding and improving the integration and management of any chronic disease is the multi-faceted layers extending from the micro level of the individual, the practitioner, and the policy maker, to a larger macro health care system.\textsuperscript{75} One of the most widely used conceptual frameworks in health services research is the Andersen Behaviour model (hereafter referred to as the Andersen Model).\textsuperscript{76} The Andersen model is helpful in identifying factors within the external environment, population, and health behaviours which then subsequently influence individual health status and utilization outcomes (see Figure 1.1).\textsuperscript{76}
The Andersen model includes feedback loops acknowledging that its components are interrelated. It also considers that within the population characteristics component, there are three important sub-components. *Pre-disposing* characteristics are factors that influence an individual to exhibit a particular health behaviour (such as health beliefs and self-efficacy). *Enabling* resources can include either community (e.g., urban, rural, distance to health services) and/or individual factors that may promote an individual to have improved health outcomes such as sociodemographics. *Need* factors are key components of this model and can be subjective and/or objective which influence health behaviour (i.e., age, injury severity, number of secondary complications, number of comorbidities).

**Network Episode Model**

While the Andersen model helps identify general factors associated with health behaviour and outcomes; it is somewhat limited in conceptualizing factors that are more *process-oriented* at the micro or patient level.\(^{60,72,73,76,77}\) To conduct integration of care research, there is a need to extend beyond the Andersen model. Specifically, there is a gap in examining micro formal and informal networks of care, as well as the extent to which patients are linked to health care services and community groups\(^ {60,78,79}\). While the application of networks of care research has increased in recent years\(^ {69,80,81}\), most has focused on inter-organization networks such as relations among community health centers, hospitals, and physician groups\(^ {82-88}\), as well as information diffusion networks.\(^ {89,90}\)

To address this limitation Pescosolido’s (1991) Network Episode Model (NEM; see Figure 2) provides a conceptual guide by acknowledging the *interdependency* and *context* that exists between individuals and their journeys/patterns of health care.\(^ {79}\) *Context* has been
suggested to be extremely important in understanding care provider networks and the processes related to care.  

The NEM (Pescosolido, 1991) considers interactions of the health care environment by including formal and informal networks of care, individual level factors, as well as the ‘journey of care’ (referred to as ‘illness career’ in Pescosolido’s model. A journey of care is defined as a complex series of interactions that comprise the processes of care. The NEM provides a framework for examining the way in which these formal and informal networks of care are structured (i.e., who comprises the network, what is the role of this person in relation to others in the network), and the process of these care interactions, their associated functions and how they may influence health behaviour and outcomes. Also important is the overall process of care, which has been called the ‘journey’ of care.  

Based on social network theory, the NEM highlights the importance of community network structures, content and processes (hereafter referred to content), as well as related functional outcomes as dynamic components that influence health behaviors and health outcomes. There are four underlying assumptions to this model, (1) communities contain care providers; (2) process of care is dynamic, occurs over time, and develops into patterns and pathways; (3) underlying the processes of health care use are social networks; (4) ‘bounded rationality’- in addition to individuals, social networks may be active forces that influence how interactions with the care providers occur. This latter assumption of the NEM differs from the Andersen model, which perceives individuals as having choices in their entrances into the health care system. While the NEM does not negate the role of the individual as an active agent, it recognizes that social influences can be as equally, if not more important.
It is important to note that the NEM was conceptualized to supplement pre-existing multifactoral health care use models such as the Andersen Model. The importance of individual characteristics, health behaviour and outcomes should be still emphasized; however, the NEM bridges these components by examining the underlying social networks and processes that influence interactions with the health care system. The NEM contributes to our understanding of how individuals obtain formal and informal health care within the context of “community-based influences, and the impact of contingencies that may shape both modes of entry and social networks” (p. 277).

Similar to Andersen’s model, the NEM has four domains, social context, social support system (informal networks), the treatment system (formal networks) and the journey of care (illness career). Networks are conceptualized by structure (i.e., size), content (strength of relationships, attributes of relationship) and respective functions (the outcome of interaction such as advice, physical or emotional assistance, satisfaction with relationship).

**Application of NEM**

Importantly, understanding the extent to which social systems influence health is just as critical as examining the more bio-medical risk factors of illness. Social capital, defined as “features of social organization, such as trust, norms, and networks that can improve efficiency of society by facilitating coordination and cooperation for mutual benefit” (p.66) is an important construct in understanding social context. Broadly, social capital is a multi-faceted construct that relates to social relationships and the resources obtained through these relationships.

Social networks are key building blocks to social capital. Studying social networks, both formal and informal networks of care, as well as the patterns of their interactions have been
The revolving door phenomenon with the mental health population is suggestive of fragmented care. There is evidence to suggest that mental health care networks, either formal and/or informal can influence mental health care utilization and negative mental health outcomes. Specifically, network size and function (i.e., perceived support) has been suggested to influence mental health care use. For example, Pescosolido et al. investigated formal and informal networks and patterns of mental health care use for low income Puerto Ricans with diagnosed mental health problems. Individuals with larger and more supportive informal networks of care had decreased visits to formal mental health providers. Based on this research, Pescosolido concluded that the social networks triggered the social influence but it was the context specifically which determined the direction of association (i.e., the increase or decrease of health care use).

Recently, Bonin and colleagues used the NEM to examine mental health utilization among homeless individuals living in Quebec. These researchers were interested in examining factors that influenced health care use among those who were impoverished with a mental health disorder in a universal health care system. Using a social network measure, the Arizona Social Support Instrument Survey, the need for social support, the size and type of social support, as well as satisfaction of social support were measured among individuals who...
used homeless services. With the exception of illness history, each component of the NEM significantly predicted utilization of mental health services.

Importantly, Bonin et al.’s study highlights a few key points. Firstly, the researchers demonstrated that the NEM can be a useful guide in predicting health care use in the Canadian context. Secondly, beyond economic barriers, networks of care were significantly associated with health care use for those with mental health problems. Based on these findings, Bonin et al. suggest that the application of the NEM to identify factors associated with high health care use may be beneficial for studying other vulnerable populations with chronic care needs. Understanding these dynamic interconnected factors such as the structure of care networks and their overall function are important, especially for populations that have frequent interactions with the health care environment. Individuals who have suffered a SCI who are living in the community are one such population with high health care utilization. Over the past 60 years, there has been a dramatic shift in critical care management of SCI which has resulted in a 40% decline in mortality during the first two years post injury. Due to these advancements and the increase in acute survivorship, SCI is now considered a chronic disease that involves a broad range of motor, sensory, and autonomic impairments. Thus, the NEM may be useful with SCI given the similarities with the mental health population such as high health care utilization, potential fragmented care, as well as dealing with mental health challenges related to the disability.

**SUMMARY AND IMPLICATIONS**

We currently know that individuals with SCI have significant SHCs and high health care utilization. SHCs continue to be problematic in approximately 20% of this population and with more than 50% self-reporting spasticity, pain, bladder infections in the past year and for
several SHCs including pressure ulcers and autonomic dysreflexia, the odds of developing these SHCs increased per year post injury.\textsuperscript{22} Despite the relatively low prevalence of SCI, the burdens imposed on the individual and health care system are significant as demonstrated by high health care utilization, decreased quality of life, and considerable financial costs.\textsuperscript{39,106,107} While we know that SHCs are likely influencing health care use, we do not know what community factors are associated with these SHCs as there is a paucity of research that has examined these issues. Understanding care provision in the community is important, especially given the shift from inpatient to community care with accompanying earlier discharges home for this population. These SHCs may in part be due to fragmented care, and insufficient access to tertiary evaluation and/or primary care management. Given the relationship between ED use and primary care health services, it is also important to understand patterns of ED use over a significant period for persons with SCI. Currently, there remains a significant gap in the literature related to examining patterns of care and characteristics of ED use in persons with SCI living in the community. This information is critical to addressing gaps in service delivery for the prevention and management of SHCs.

Thus, this literature review has identified a need to describe and understand in more detail the community networks and pathways of care at the individual (micro) level, care providers (meso level) and macro level (health system) for community-dwelling persons with SCI. To date, the NEM perspective has not been applied beyond mental health and there are several important implications in doing so. One, this approach will highlight formal and informal network characteristics. Two, insight will be gained on the journey of care related to SHCs. Three, this micro level analyses will highlight gaps in care provision, especially for marginalized sub-groups (i.e., low income, high disability) and areas that may need inter-sectoral
integration/coordination to improve service delivery and efficiency. Four, by understanding these networks of care and how they may relate to health care utilization and outcomes, recommendations to improve the management of care for the SCI population at the individual, provider and policy level can be made. Fifth, this research will inform future deductive studies. Finally, applying this multi-level network approach to SCI can help inform its application to other chronic disease populations requiring an integrated care approach.

Overview of study to address important gaps in the literature

There remains a significant gap in the SCI literature related to community care provision and outcomes, such as SHCs, health care utilization, and quality of life. In fact, we have minimal published knowledge as to how care is managed in the community and the associated patterns of care. To address this research gap, the purpose of the study detailed in this thesis was to describe networks of care and the journey of care at the micro, meso and macro levels for persons with SCI living in the community.

Thesis Questions

1. What are the patterns and characteristics of ED visits for persons with SCI living in the community? Are these ED visits related to potentially preventable SHCs that could be managed in the primary health care setting? (Chapter 2)

2. What are the informal and formal networks of care for persons with SCI living in the community? (Chapter 3)

3. What are the roles of these caregiving networks in the prevention of and/or management of SHCs? (Chapter 3)

4. Once individuals with SCI are discharged into the community, what is the journey of care in the prevention of and/or management of SHCs? (Chapter 4)
Assumptions

Based on the literature review, there are several assumptions that underlie the proposed research. First, high primary health care utilization, readmissions and ED visits reflect poor integration of care. With respect to the SCI population, high utilization and readmissions are likely due to SHCs. Second, these SHCs are mostly preventable such that improved integration of care will minimize adverse events such as SHCs, readmissions, and ED visits. Third, poor integration of care and related adverse events negatively impacts the journey of care and the person with SCI’s overall quality of life.

Overview of study design and data

I used a mixed method single exploratory case study design to understand how networks of care influence the journey of care related to secondary complication management. Case study design is ideal for understanding a phenomenon in more complex detail and gaining insight into the contextual factors that may be related to the research question. For this research study, the province of Ontario was defined as the case under inquiry. The province of Ontario is situated in central Canada and has a population of approximately 13 million inhabitants and represents approximately 40% of the Canadian population.

Theoretical Position

The theoretical approach underlying this study was that of relativist ontology, that is, previous a priori knowledge helped inform assumptions but allowed for emerging themes to arise. The paradigm guiding this research question was a naturalistic interpretive one. This multi-lens approach was concerned with understanding the subjective, complex, and contextual experiences of participants. The contextual and constructed realities of each participant
helped inform and reshape knowledge gained from the research inquiry.\textsuperscript{113,114} Further, principles from Thorne’s interpretive description methodology facilitated the scientific inquiry, as this approach allowed for \textit{a priori} assumptions (e.g., network episode theory) to be synthesized with knowledge gained from data, as well as other theoretical and contextual health services clinical knowledge.\textsuperscript{113,114}

\textit{Data}

\textbf{Administrative data}

Administrative healthcare databases from Ontario, Canada, were used for the first paper are described below. Hospitalization records were obtained from the Canadian Institute for Health Information (CIHI) Discharge Abstract Database (DAD), which contains a detailed record of all hospital admissions from over 200 acute hospitals in Ontario. Every hospital record in the dataset contains a patient’s health card number, age, sex, postal code, date of admission, date of discharge, and most responsible diagnostic codes (based on International Classification of Disease, Tenth Revision Canada (ICD-10-CA) codes).\textsuperscript{9} Outpatient physician visits were identified using the Ontario Health Insurance Plan (OHIP). The main data elements included in a physician billing claim are patient and physician unique identifying number, date of the service/claim, fee code for service provided, and fee paid. The Ontario Registered Persons Database (RPD) contained basic demographic and vital statistics information, including death date, for each Ontario resident. The National Ambulatory Care Resource System (NACRS) database provided information on all visits to the ED and the main data elements are reasons for the ED visit and patient demographics. All databases were linked anonymously using encrypted individual health card numbers.
Key informant interviews

Semi-structured key informant interviews provided the primary source of data for papers 2 and 3. Key informants included persons with a SCI living in the community, formal and informal care providers, case managers, administration/executive managers, policy-makers and decision makers. The recruitment strategy included purposeful snowball sampling for maximum variation in stakeholder experiences.\textsuperscript{108} In particular for persons with SCI, we specifically aimed to have fair representation across gender, level of injury (cervical, thoracic, lumbar), and mechanism of injury (traumatic and non-traumatic), as well as socioeconomic status/funding source for health care services (private payments from motor vehicle accident compensation, public payment for services). Key informant interviews were conducted in two phases. The first phase involved interviews with persons with SCI. We initially recruited in the community by advertising the study via the Canadian Paraplegic Association (CPA)-Ontario division’s website and email distribution. The second phase of interviews involved formal and informal care providers, case managers, and policy/decision makers. A preliminary list of key informants for this phase was developed by the research team and increased with snowball sampling techniques. In this second phase, key informants were those individuals with detailed knowledge of processes involved in the journey of care regarding SHCs for individuals with SCI.

Document analysis

In addition to key informant interviews, documents were reviewed as another source of data. These documents provided data to assist with comparing and contrasting data obtained from key informant data. Considerable efforts were made to review documents from multiple sources (e.g., websites, brochures, gray literature).
Overview of the thesis

The remainder of the thesis presents the results of the study in the form of three distinct papers (Chapters 2-4), as summarized below. The final chapter (Chapter 5) provides an overall discussion of the relevance of the findings to key stakeholders in the SCI community, such as those with SCI, those who provide care and/or support for persons with SCI and health care decision and policy makers. Finally, limitations of the overall study and recommendations for future research will be discussed.

Chapter 2. (Paper 1).

Title: Is the Emergency Department an Appropriate Substitute for Primary Care for Persons with Traumatic Spinal Cord Injury?

The purpose of this paper was to address the gap in the literature regarding understanding ED use for community-dwelling persons with TSCI in Ontario. This information is critical to addressing gaps in service delivery for the prevention and management of SHCs. The objective of this study was to describe the patterns (e.g., number of visits by year post injury) and characteristics of ED visits (e.g., acuity level, timing of visits, reasons for visits) made by persons with TSCI over a 6 year period following injury.

Chapter 3. (Paper 2).

Title: Social Networks and Secondary Health Conditions: The Critical Secondary Team for Individuals with a Spinal Cord Injury

The purpose of this paper was to describe community networks for community-dwelling individuals with SCI. To the best of our knowledge, social network theory has not been applied to SCI research. This approach will highlight informal network characteristics and how these
networks influence the prevention of and/or management of SHCs. Specifically, the objectives for this study were to: describe the structure of informal networks (e.g., size and type of care providers) for individuals with SCI living in the community; (2) explore the quality of relationships of informal networks; and (3) explore the role of informal networks in the prevention and management of SHCs.

Chapter 4. (Paper 3).

Title: Dealing with secondary health conditions and spinal cord injury: An uphill battle in the journey of care

The purpose of this paper was to examine the journey of care related to SHCs for persons with SCI living in Ontario. Thus the primary objectives of this study were to describe the journey of care related to the prevention and/or management of SHCs for community-dwelling persons with SCI and to understand factors at the micro (individual), meso (care provider) and macro (health system) level that may influence the journey of care.
Figure 1.1: Andersen’s conceptual framework of health services utilization
Figure 1.2: Pescosolido’s Network Episode Model
Chapter 2: PAPER 1

TITLE: Is the Emergency Department an Appropriate Substitute for Primary Care for Persons with Traumatic Spinal Cord Injury?

Abstract

Objectives: To describe the patterns (e.g., number of visits by year post injury) and characteristics of ED visits (e.g., acuity level, timing of visits, reasons for visits) made by persons with TSCI over a 6 year period following injury.

Methods: Using a retrospective cohort with administrative data, rates of ED utilization and reasons for ED visits were calculated between the fiscal years 2003-2009 for persons with TSCI. Reasons for visits were categorized by acuity level: potentially preventable visits were defined as visits related to ambulatory sensitive conditions; low acuity and high acuity visits were defined by the Canadian Triage and Acuity Scale.

Results: The total number of ED visits for the six year period is 4403 (n=1217). Of these visits, 752 (17%) were classified as potentially preventable, 1443 (33%) as low acuity and 2208 (50%) as high acuity. The majority of patients, regardless of acuity level, did not see a family/general practitioner on the day of the ED visit. The majority of ED visits occurred during the weekday (Mon-Fri 07:00-16:59). ED use was highest in the first year following injury but remained high over the subsequent years. For potentially preventable visits, the majority of visits were related to urinary tract infections (n=385 visits, 51.2%), followed by pneumonia (n=91, 12.1%).

Conclusions: Given the high prevalence of secondary health conditions, and the high rates of ED use for low acuity and potentially preventable conditions, these results suggest that the ED is being used as an inappropriate substitute for primary care for individuals with TSCI 50% of the time.
INTRODUCTION:

Persons with disabilities, such as those with traumatic spinal cord injury (TSCI), face numerous challenges in navigation through the primary care health care system. Primary care serves a vital role as the first-contact with the health system and is important for health promotion, prevention, diagnosis and treatment. In the general population, rates of emergency department utilization have been used as indicators of accessibility, availability and/or integration of primary care services. For persons with TSCI, the high rates of rehospitalization, and the frequency and severity of preventable secondary health conditions (SHCs) suggest there are deficiencies in care for this population, of which insufficient primary care is presumed to be one of the key drivers.

While many of these SHCs are preventable and/or responsive to appropriate primary care management, such as urinary tract infections, pressure ulcers, pain, they are purported to be key contributors for re-hospitalizations and/or death in the post-acute phase. The initial transition period, typically within 18 months of injury, has been suggested to be a critical phase in the development of SHCs and increases the likelihood of the individual’s interactions with the healthcare system. In the US, the average rehospitalization rate within the first year of injury was 55% decreasing to 37% after five years. Similarly, the frequency of ED and physician visits in Canada are high in this same time period. However, SHCs continue to be problematic in approximately 20% of this population and with more than 50% self-reporting spasticity, pain, bladder, infections in the past year and for several SHCs including pressure ulcers and autonomic dysreflexia, the odds of developing these SHCs increased per year post injury.
Thus, these SHCs may in part be due to fragmented care, and insufficient access to tertiary evaluation and primary care management. Given the relationship between ED use and primary care health services, it is important to understand patterns of ED use over a significant period for persons with TSCI. Currently, there remains a significant gap in the literature related to examining patterns of care and characteristics of ED use in persons with SCI living in the community. This information is critical to addressing gaps in service delivery for the prevention and management of SHCs. The objective of this study was to describe the patterns (e.g., number of visits by year post injury) and characteristics of ED visits (e.g., acuity level, timing of visits, reasons for visits) made by persons with TSCI over a 6 year period following injury.

METHODS:

Setting

A universal publicly funded health care system in the province of Ontario, with over 13 million residents, representing approximately 40% of the Canadian population.

Design

This study used a retrospective cohort design. Prevalence, sociodemographics, impairment characteristics and emergency department patterns of Ontarians with TSCI were examined and compared for the fiscal years 2003/04 to 2008/09 (April 1st 2003 to March 31st, 2009).

Privacy/Ethics

This study was approved by the institutional Research Ethics Board.

Data Sources

Administrative healthcare databases from Ontario, Canada, were used for this study and described below. Hospitalization records were obtained from the Canadian Institute for Health
Information (CIHI) Discharge Abstract Database (DAD), which contains a detailed record of all hospital admissions from over 200 acute hospitals in Ontario. Every hospital record in the dataset contains a patient’s health card number, age, sex, postal code, date of admission, date of discharge, and most responsible diagnostic codes (based on International Classification of Disease, Tenth Revision Canada (ICD-10-CA) codes). Outpatient physician visits were identified using the Ontario Health Insurance Plan (OHIP). The main data elements included in a physician billing claim are patient and physician unique identifying number, date of the service/claim, fee code for service provided, and fee paid. The Ontario Registered Persons Database (RPD) contained basic demographic and vital statistics information, including death date, for each Ontario resident. The National Ambulatory Care Resource System (NACRS) database provided information on all visits to the ED and the main data elements are reasons for the ED visit and patient demographics. All databases were linked anonymously using encrypted individual health card numbers.

**Study Population**

Individuals with TSCI admitted to Ontario hospitals between April 1, 2003 and March 31, 2009 were included in the cohort. Index cases were identified from acute care hospitalization records using ICD-10-CA diagnostic codes for SCI that have been previously used to determine TSCI incidence in Ontario. Records were excluded if: gender was missing, age at index admission for SCI was less than 18 years), previous hospital stay for TSCI, index admission was not classified as the main reason for admission, died within index hospital admission, discharged after March 31st, 2009, and/or repeated admission record.
**Demographic Variables**

Individual level variables included the following: age, sex, income quintile, rurality (RIO), injury level (cervical/thoracic/lumbar/other), concurrent traumatic brain injury (TBI), Charlson comorbidity index Deyo-Adaption for administrative data,\textsuperscript{121} direct discharge to short-stay or long-stay rehabilitation, and length of stay of index admission (admission to discharge). The Rurality Index of Ontario (RIO) is a scaled index based on population factors and distance (ranges 0-100), and communities with higher values (cut point ≥ 45) are more rural.\textsuperscript{122} Income levels are imputed from Census data, with the Ontario population is divided into income quintiles with 1 being the lowest and 5 being the highest.\textsuperscript{123}

**Total ED Visits by Year**

The number of ED visits was counted for individuals from the date of index discharge from acute care to March 31\textsuperscript{st}, 2009. Individuals were assigned to a “sub-cohort” based on the fiscal year of their index hospitalization, but the ED visits were stratified by one-year increments from index discharge. In other words, the follow-up window is unique to each individual, with the start of the window being the day after discharge and the end being 365 days after discharge; then 366 days after discharge is the start of year 2, etc.

**Visit Types and Characteristics**

*Potentially preventable, low acuity, and high acuity visits*

ED visits were classified as potentially preventable, low acuity and high acuity based on previous work examining ED use among nursing home residents.\textsuperscript{124} Potentially preventable visits were defined as visits to the ED for Ambulatory Care Sensitive Conditions (ACSC) which are conditions that likely could have been managed by timely and effective primary care. ACSC are
frequently used as indicators of lack of primary care access.\textsuperscript{125,126} These conditions included diagnosis codes for: grand mal status and other epileptic convulsions, chronic obstructive pulmonary disease, acute bronchitis, pneumonia, asthma, heart failure and pulmonary edema, hypertension, angina and diabetes\textsuperscript{127} (see Appendix A for detailed list of codes and respective exclusions). The Canadian Triage and Acuity Scale (CTAS) was used to define low and high acuity. The CTAS is a standardized measure of urgency for care in NACRS and the CTAS is administered to all persons visiting the ED.\textsuperscript{128} Low acuity visits were defined as those visits with a CTAS score of 4 or 5 (less or non-urgent) and high acuity visits 1 to 3.

\textit{Visit Characteristics}

ED records were linked to physician billings to ascertain whether patients were seen by a physician on the day of the ED event. The timing of visit was captured by identifying the day and time of the visit: weekday (Mon-Fri 07:00-16:59), weeknight (Mon-Fri 17:00-06:59), weekend day (Sat, Sunday 07:00-16:59), weekend night (Sat, Sunday 17:00-06:59), and weekend (Friday 17:00 - Mon 06:59). The most common procedure was determined by the highest percentage of all the recorded procedures performed during the visits. Discharge location (admitted to a hospital, died, discharged home, discharged to a residence, or other) was identified. The ten most-frequent reasons for ED visits were determined by the first three digits of the ICD-10-CA codes.

\textit{Analysis}

There were two main analyses for this study: 1) a longitudinal analysis which examined trends in ED use over time since injury; 2) an aggregated analysis of all ED visits in the study period. The number of individuals per fiscal year were identified and compared on socio-demographic variables (sex, age, etiology of injury, level of injury, Charlson Index, traumatic
brain injury diagnosis, discharge disposition from index acute setting, rurality, income quintile, length of acute care stay). For each fiscal year sub-cohort, the following variables were calculated for every one-year increment of follow up data available from the index discharge date: the rate of ED visits (calculated by the number of visits per 100 persons, percentage of cohort with at least one visit to the ED, number of deaths, and number lost to follow up. Individuals who died or were lost to follow-up were censored, such that any ED visits during the incomplete year were not included in the ED visit count for that particular year; however, these visits of censored individuals were captured in the aggregated analysis.

Descriptive statistics were used to describe the type and characteristics of ED visits. All analyses were conducted using SAS 9.2 (SAS Institute, Inc., Cary, NC).

RESULTS

Demographics and clinical characteristics

There were 1515 TSCI index cases that met our inclusion criteria and 1217 were classified as incident cases (see Appendix B). Figure 2.1 shows the number of each sub-cohort by fiscal year. Table 2.1 shows the demographics and clinical characteristics of each sub-cohort by fiscal year as well as the overall cohort (N=1217). Among the overall cohort, the majority were male (n=912; 74.9%), had an injury at the cervical spine level (n=773, 63.5%), Charlson index of 0 (n=796; 65.4%), and lived in an urban setting (n=976, 80.2%). There were no major differences in any of these characteristics by fiscal year.

ED Utilization Stratified by Years Post Injury

In the first year following a TSCI, the number of visits per 100 persons ranged from 88 (fiscal year 2004/05) to 122 (fiscal year 2008/09; see Table 2.2). ED visits were generally more frequent in the first year following a TSCI, regardless of the fiscal year in which the injury
ED use was higher for individuals living in a rural area compared to those in more urban settings. Similar to previous results, the number of ED visits per 100 persons was highest in the first year following injury (rural-126 visits/100 persons; urban- 106 visits/100 persons), and decreased slightly for the subsequent years. For example, four years post-injury, the number of rural visits was 109 per 100 persons, urban visits were 72 per 100 persons and 5 years post injury, visits were 100 and 65 per 100 persons, respectfully. Similar patterns were observed in ED use over the years following injury for gender, and age (18-39, 40+), as ED use was highest in the first year following injury but remained high over the subsequent years (see Figure 2.2).

Characteristics of ED Visits

The total number of ED visits between April 1, 2003 and March 31, 2009 is 4403 (Table 2.3). Of these visits, 752 (17%) were classified as potentially preventable, 1443 (33%) as low acuity and 2208 (50%) as high acuity. The majority of individuals, regardless of acuity level, did not see a family/general practitioner on the day of the ED visit. Further, the plurality of ED visits occurred during the weekday (Mon-Fri 07:00-16:59). Of the procedures recorded, the most common procedures performed during the ED visit were related to x-ray imaging without contrast (thoracic cavity, abdominal cavity, spinal vertebrae). Overall, the majority of individuals were discharged home (66.3% (64.9-67.6)).
The top five reasons for ED visits by acuity are shown in Table 2.4. For potentially preventable visits the majority of visits were related to urinary tract infections (n=385 visits, 51.2%), followed by pneumonia (n=91, 12.1%). Low acuity visits were mostly due to pain-related reasons (n=153 visits, 10.6%), as well as prescription refills (n=138 visits, 9.6%). Pain-related reasons (pain in chest or throat, abdominal and pelvic pain, dorsalgia) contributed to a significant number of high acuity visits (n=300, 13.6%).

**DISCUSSION**

In this population-based study, we identified high rates of ED visits for several years following the initial TSCI. The number of visits was higher in the first year following injury, with 110 visits per 100 persons (45.3% of sample visited the ED), and remained substantially high up until six years following injury (34.5% of sample six years post injury visited ED). Given the nature of the injury, high health care utilization in the first year following injury is expected but our results show that individuals are still utilizing the ED at similar high rates many years following injury. Further, ED utilization patterns did not vary significantly by gender or age. These ED rates are higher than the general population in Ontario with an average of 39.7 visits per 100 population. With respect to acuity level, approximately 50% of visits are emergent or urgent in nature for persons with a SCI, which are similar to the general population in Ontario, as 43% of visits classified as emergent/urgent.

Differences in ED patterns were observed based on the rurality index, as higher ED use was noted for individuals living in rural areas compared to those in more urban settings. This finding is consistent with previous literature as access to and availability of primary care physicians are more challenged in rural than in urban centres. In our previous work, we identified rurality as a significant predictor of ED utilization within the first year following a SCI.
in both the traumatic and non-traumatic population. One plausible explanation is that individuals living in rural communities may not have access to a regular primary care physician, thereby resulting in increased ED use to address primary care needs. However, a recent report that examined accessibility of rural and northern communities within Ontario showed that 99.6% of those living in rural communities with populations of 30,000 or less had access to a primary care provider within a 30 minute driving distance.

While distance to primary care services may not be an issue, other barriers to primary care include, (1) physical inaccessibility of office facilities (such as lack of wheelchair ramps, narrow door frames, insufficient turning radius in exam rooms and lack of high-low examination tables), (2) attitudinal (e.g. unwillingness to provide care), (3) expertise (e.g. inadequate knowledge of disability), and (4) systemic (e.g., policies that systematically exclude, lack of available services). These barriers may influence the choice of location for care. For example, if individuals need to have diagnostic imaging and/or blood work, it would be more time efficient to go to the ED for a ‘one-stop shop’ rather than first visiting the primary care physician for a requisition and then going to another location to have the test and going back to receive the test results.

Our results showed that regardless of acuity level, most individuals did not see a primary care physician on the day of the ED visit, despite the fact that the plurality of visits occurred during the weekday working hours. Particularly important for the 50% of visits classified as potentially preventable and/or low acuity, individuals may have accessed their primary care providers to address their health care needs rather than utilizing ED services. Utilizing ED services for prescription refills, for example, is not a cost-effective use of health care services. Alternately, the lack of rural diagnostic services may prompt direct ED visits. Future studies on
availability of services and access are needed to understand the reasons for the current pattern or
preventable or low acuity ED visits. For example, are persons going to the ED because they
cannot ascertain the level of acuity at the time of decision-making? Or perhaps there is a lack of
confidence in the primary care provider, as previous literature suggests,\textsuperscript{133,134} which may
encourage individuals to seek care in the ED?

Decreased access to primary care has been suggested to influence high ED utilization
rates in other vulnerable populations with complex needs.\textsuperscript{135,136} The use of ED resources for
preventable primary care conditions has implications for the coordination of care between that of
emergency department physicians and primary care professionals.\textsuperscript{137} In particular, the
fragmentation of care poses risks for duplicative treatment, misapplied treatment as well as cost-
ineffective management. For example, if individuals with complex SHCs are using the ED as a
primary source for condition management, primary care professionals are not able to address
prevention strategies for chronic condition management.\textsuperscript{137}

There are a few methodological limitations to this study. While the ACSC codes have
been validated in the general population and for the geriatric population, these conditions have
not been specifically validated in the context of TSCI as potentially preventable. Given the
importance of understanding the role of primary care in the prevention and management of SHCs
after TSCI this would be important future research. Finally, due to limitations in available data,
a longer-term follow-up was not possible, as well as identifying whether individuals had a
regular general practitioner.

**CONCLUSIONS**

This is the first study that has examined ED utilization patterns and characteristics for
persons with TSCI over an extended time period. Given the high prevalence of SHCs, and the
high rates of ED use for low acuity and potentially preventable conditions, these results suggest that the ED is being used as an inappropriate substitute for primary health care for individuals with TSCI.
Table 2.1: Socio-demographic and clinical characteristics of TSCI, fiscal years 2003/04 to 2008/09

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<tr>
<td>Mean ± SD</td>
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<td>49.7 ±19.2</td>
<td>48.2 ±19.0</td>
<td>51.6 ±19.1</td>
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<tr>
<td>Female</td>
<td>45 (25.6%)</td>
<td>47 (24.0%)</td>
<td>53 (25.9%)</td>
<td>61 (28.1%)</td>
<td>49 (21.8%)</td>
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<td>Male</td>
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<td>156 (71.9%)</td>
<td>176 (78.2%)</td>
<td>148 (74.7%)</td>
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<td><strong>Injury Level</strong></td>
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<td>Cervical SCI</td>
<td>110 (62.5%)</td>
<td>122 (62.2%)</td>
<td>132 (64.4%)</td>
<td>139 (64.1%)</td>
<td>136 (60.4%)</td>
<td>134 (67.7%)</td>
<td>773 (63.5%)</td>
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<td>Thoracic SCI</td>
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<td>45 (23.0%)</td>
<td>53 (25.9%)</td>
<td>49 (22.6%)</td>
<td>54 (24.0%)</td>
<td>40 (20.2%)</td>
<td>277 (22.8%)</td>
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<td>Lumbar SCI</td>
<td>22 (12.5%)</td>
<td>22 (11.2%)</td>
<td>17 (8.3%)</td>
<td>24 (11.1%)</td>
<td>26 (11.6%)</td>
<td>16 (8.1%)</td>
<td>127 (10.4%)</td>
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<tr>
<td>Other SCI</td>
<td>8 (4.5%)</td>
<td>7 (3.6%)</td>
<td>&lt;= 5</td>
<td>&lt;= 5</td>
<td>9 (4.0%)</td>
<td>8 (4.0%)</td>
<td>40 (3.3%)</td>
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<td><strong>Charlson Index</strong></td>
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<td>22.7 ±31.1</td>
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<td>22.8 ±30.4</td>
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<td>14 (8-27)</td>
<td>15 (7-26)</td>
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<td>123 (62.1%)</td>
<td>756 (62.1%)</td>
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*does not add to 100% due to missing data
†Index LOS= length of stay of index hospital admission
Table 2.2. Overall patterns of emergency department utilization, fiscal years 2003/04 to 2008/09

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<td>139</td>
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<td>% who visited ED</td>
<td>46.3%</td>
<td>41.9%</td>
<td>35.8%</td>
<td>33.8%</td>
<td>37.1%</td>
<td>34.8%</td>
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<td>177</td>
<td>174</td>
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<td>46.7%</td>
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<td>37.4%</td>
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<td>High Acuity* (CTAS 1-3)</td>
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<td>Xray, thoracic cavity without contrast</td>
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<td>22.3 (21.1-23.5)</td>
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<td>Xray, spinal vertebrae without contrast</td>
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<td>4.5 (3.9-5.1)</td>
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<td>4.2 (3.6-4.8)</td>
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</tr>
<tr>
<td>Died</td>
<td>0.4 (0.1-0.7)</td>
<td>0.1 (0.1-0.2)</td>
<td>0.1 (0.1-0.4)</td>
<td>0.2 (0.1-0.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>58.7 (56.7-60.8)</td>
<td>80.9 (78.9-83.0)</td>
<td>60.1 (56.6-63.6)</td>
<td>66.3 (64.9-67.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long term care residence</td>
<td>5.7 (4.7-6.7)</td>
<td>5.0 (3.9-6.1)</td>
<td>5.7 (4.1-7.4)</td>
<td>5.5 (4.8-6.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>9.1 (7.9-10.3)</td>
<td>7.6 (6.2-8.9)</td>
<td>2.8 (1.6-4.0)</td>
<td>7.5 (6.7-8.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Died within 30 days of ED visit (if alive at discharge)</td>
<td>3.0 (2.3-3.7)</td>
<td>0.6 (0.2-1.0)</td>
<td>4.4 (2.9-5.9)</td>
<td>2.5 (2.0-2.9)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Canadian Triage Acuity Scale measured at the time of ED intake registration
* Number of visits to ED
** Top six most commonly reported procedures recorded during visit, denominator is all procedures
CI= Confidence Interval; CTAS=Canadian Triage Acuity Scale
Table 2.4: Top five most common reasons for emergency department (ED) visits

<table>
<thead>
<tr>
<th>Reason for Visit</th>
<th>Frequency (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Potentially Preventable (N = 752)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urinary tract infection (N390)</td>
<td>385</td>
<td>51.2</td>
</tr>
<tr>
<td>Pneumonia (J189)</td>
<td>91</td>
<td>12.1</td>
</tr>
<tr>
<td>Non-infective gastroenteritis and colitis (K529)</td>
<td>42</td>
<td>5.6</td>
</tr>
<tr>
<td>Cellulitis of lower limb/upper limb (L0311, L0310)</td>
<td>30</td>
<td>4.0</td>
</tr>
<tr>
<td>COPD with acute exacerbation, unspecified (J441, J449)</td>
<td>26</td>
<td>3.4</td>
</tr>
<tr>
<td><strong>Low Acuity Visits (N = 1443)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain (M54, R52, M79, R10)</td>
<td>153</td>
<td>10.6</td>
</tr>
<tr>
<td>Persons encountering health services in other specified circumstances (Z76)²</td>
<td>142</td>
<td>9.8</td>
</tr>
<tr>
<td>Fitting and adjustment of other devices (Z46)¾</td>
<td>34</td>
<td>2.4</td>
</tr>
<tr>
<td>Complications of genitourinary prosthetic devices (T83)</td>
<td>29</td>
<td>2.0</td>
</tr>
<tr>
<td>Decubitus ulcer (L89)</td>
<td>28</td>
<td>1.9</td>
</tr>
<tr>
<td><strong>High Acuity Visits (N = 2208)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain (R07, R10, M54)</td>
<td>300</td>
<td>13.6</td>
</tr>
<tr>
<td>Abnormalities of breathing (R06)</td>
<td>51</td>
<td>2.3</td>
</tr>
<tr>
<td>Functional intestinal disorders (K59)</td>
<td>49</td>
<td>2.2</td>
</tr>
<tr>
<td>Mental and behavioural disorders due to use of alcohol (F10)</td>
<td>45</td>
<td>2.0</td>
</tr>
<tr>
<td>Sepsis (A41)</td>
<td>42</td>
<td>1.9</td>
</tr>
<tr>
<td>Retention of urine (R33)</td>
<td>42</td>
<td>1.9</td>
</tr>
</tbody>
</table>

¹Issue of repeat prescription (N = 138), Malingerer (N = 2), Other specified circumstances (N = 2)
²Urinary (N = 31), Intestinal (N = 1), Orthopedic (N = 1), Other (N = 1)
Figure 2.1: Number of persons with traumatic spinal cord injury identified by years post injury
Figure 2.2: Emergency department (ED) visits per 100 persons by years post injury

*The mean number of visits per 100 persons is denoted by the middle tick, with the upper and lower ticks identifying the 95% confidence intervals.
Figure 2.3: Emergency department (ED) visits per 100 persons by years post injury, stratified by demographics
Chapter 3: PAPER 2

TITLE: Social Networks and Secondary Health Conditions: The Critical Secondary Team for Individuals with a Spinal Cord Injury

Abstract

Objectives: To describe the structure of informal networks for individuals with spinal cord injury (SCI) living in the community, to understand the quality of relationships of informal networks, and to understand the role of informal networks in the prevention and management of secondary health conditions (SHCs).

Methods: We used a mixed method exploratory descriptive approach. In-depth semi structured interviews were conducted with community-dwelling individuals with a SCI living in Ontario. The recruitment strategy included purposeful snowball sampling for maximum variation experiences. The Arizona Social Support Interview Survey was used to measure social networks. Participants were asked the following open-ended questions: (1) What have been your experiences with your health care in the community? (2) What have been your experiences with care related to prevention and/or management of SHCs?, (3)What has been the role of your informal social networks (friends/family) related to SHCs?

Results: Fourteen key informant interviews were conducted (6 men, 8 women). The majority of individuals (n=13; 92.8%) reported significant challenges with SHCs in the past year. The overall median for available informal networks was 11.0 persons (range 3-19). Networks were larger for social support (median=6.5), and physical assistance (median=4.0), followed by positive feedback (median=3.5), advice (median=3.0), material assistance (median=2.5) and intimate relations (median=2.5). The informal network engaged in the following roles: (1) advice/validating concerns; (2) knowledge brokers; (3) advocacy; (4) preventing SHCs; (5)
assisting with finances; and (6) managing SHCs. Participants described their informal networks as a “secondary team”, that is, a critical and essential force in dealing directly and indirectly with SHCs.

**Conclusions:** While networks are smaller for persons with SCI compared to the general population, these ties seem to be strong, which is essential when the roles involve a level of trust, certainty, tacit knowledge, and flexibility. These informal networks serve as essential key players in filling the gaps that exist within the formal health care system.
INTRODUCTION:

Spinal cord injury (SCI) involves significant change(s) with motor, sensory and/or autonomic functioning and is associated with high levels of disability. In Canada, there are approximately 44,000 individuals currently living with traumatic SCI and approximately 1100 new cases per year whereas higher incidence and prevalence rates are reported in the United States with 12,400 new cases per year and an estimated 259,000 prevalent cases. Advances in roadside management, early acute medical therapy and surgical decompression and advances in rehabilitation care have contributed to increased life expectancy and frequency of community discharge with the mean survival time reported to be more than 30 years.5

While more individuals are surviving from initial injury, this devastating chronic injury predisposes a person to multi-system impairments which can lead to the development of serious secondary health complications (SHCs) including: respiratory impairments and related infections, urinary tract infections (UTIs), respiratory infections, heart disease, osteoporosis, upper extremity overuse injuries, sleep disorders, sexual disorders such as erectile dysfunction and ejaculation among men, pressure ulcers, chronic pain, fatigue, depression and suicide. While many of these SHCs are preventable and/or responsive to appropriate primary care management, they are purported to be key contributors for re-hospitalizations and/or death in the post-acute phase.

These high utilization rates of health care services suggest that care needs in the community are not being met for this population. Given the reduced lengths of inpatient rehabilitation stay, persons with SCI often require outpatient community services to manage SHCs that have not stabilized at the time of index discharge. Indeed, this shift from inpatient care to the community has led to an increased role for formal care provision (paid medical
professionals) as well as informal networks (unpaid providers such as family, friends, and community organizations) after discharge in the community.140

Despite this shift in health service delivery to the community, to date there is a gap in the SCI literature with respect to understanding the formal and informal caregiving networks as they relate to the prevention of SHCs. Understanding the extent to which social systems influence health is just as critical as examining the more bio-medical risk factors of illness.92 Social capital, defined as “features of social organization, such as trust, norms, and networks that can improve efficiency of society by facilitating coordination and cooperation for mutual benefit”(p.66),93 is an important construct in understanding social context. Broadly, social capital is a multi-faceted construct that relates to social relationships and the resources obtained through these relationships.94

Social networks are a key building block to social capital.95,96 Studying social networks, both formal and informal networks of care, as well as the patterns of their interactions, has been useful in understanding fragmentation of care in other populations with chronic conditions, such as mental health, who have high health care utilization.60,72,73,97-100 For example, integration of mental health services in the community has been particularly challenged, as reflected by the "revolving door" phenomenon.141 This revolving-door concept is an indicator of fragmented care and refers specifically to bounce-back situations whereby patients have four or more admissions to inpatient services within a short time period (i.e., often a year or two).102

There is evidence to suggest that mental health caregiving networks can influence mental health care utilization and negative mental health outcomes.72,73,97-100 In particular, social capital measures such as network size and function have been suggested to influence mental health care use.72,73,100 For example, Pescosolido et al. investigated formal and informal networks and
patterns of mental health care use for low income Puerto Ricans with mental health problems.\textsuperscript{72,73} Individuals with larger and more supportive informal networks of care had decreased visits to formal mental health providers.

Similarly, Bonin and colleagues, using social network theory, examined mental health utilization among homeless individuals living in Quebec.\textsuperscript{100} These researchers were interested in examining factors that influenced health care use among those who were impoverished with a mental health disorder in a universal health care system. With the exception of illness history, Bonin and colleagues identified that social networks, environmental characteristics and patient demographics all significantly predicted utilization of mental health services.\textsuperscript{100}

Bonin et al.’s findings suggest that the application of social network theory to identify factors associated with high health care use may be beneficial for studying other vulnerable populations with chronic care needs, such as those with SCI.\textsuperscript{100} Understanding these dynamic interconnected factors such as the structure of care networks, the linkages within and between networks, and their overall function, especially for complex populations that “bounce” frequently throughout the health care environment are important as a means to improve integration of care.\textsuperscript{60,72,73,142} This methodology has been useful in understanding fragmentation of care such that recommendations to improve the integration of care for the SCI population at the individual, provider and policy level can then be made.

**Implications of Research**

We currently know that individuals with SCI have significant secondary complications and high health care utilization. SHCs continue to be problematic in approximately 20\% of this population\textsuperscript{27} and with more than 50\% self-reporting spasticity, pain, bladder infections in the past year and for several SHCs including pressure ulcers and autonomic dysreflexia, the odds of
developing these SHCs increased per year post injury.\textsuperscript{22} Despite the relatively low prevalence of SCI, the burdens imposed on the individual and health care system are significant, as demonstrated by high health care utilization, decreased quality of life, and considerable financial costs.\textsuperscript{106,107} While we know that SHCs are likely influencing health care use, we do not know what community factors are associated with these SHCs. Understanding care provision in the community is important, especially given the shift from inpatient to community care with accompanying earlier discharges home in this population.

This study aimed to provide comprehensive descriptive analyses of community networks for community-dwelling individuals with SCI. To the best of our knowledge, social network theory has not been applied to SCI research. This approach will highlight informal network characteristics and how networks influence the journey of care, defined as a complex series of interactions that comprise the processes of health care, as it relates to SHC management.\textsuperscript{79,91}

**Objectives:**

Specifically, this study will:

1. describe the structure of informal networks (e.g., size and type of care providers) for individuals with SCI living in the community; and
2. understand the quality of relationships of informal networks
3. understand the role of informal networks in the prevention and management of SHCs.
METHODS

We used a mixed method exploratory descriptive approach. In-depth semi-structured interviews with community-dwelling individuals with a SCI were conducted. Due to geographical and accessibility limitations, the interviews were conducted over the telephone and audio-recorded. The consumer interviews ranged from 60 to 90 minutes in length.

**Conceptual Framework: Network Episode Model**

We used Pescosolido’s (1991) Network Episode Model (NEM) as a conceptual guide for this study (see Figure 3.1), as this model acknowledges the interdependency and social context that exists between individuals, networks, and their journeys of health care. The NEM has four domains, social context (environment), social support system (informal networks), the treatment system (formal networks) and the illness career (journey of care). Based on social network theory, the NEM highlights the importance of community network structures, processes, and related functional outcomes as dynamic components that influence health behaviors and health outcomes. There are four underlying assumptions to this model, (1) communities contain care providers; (2) process of care is dynamic, occurs over time, and develops into patterns and pathways; (3) underlying the processes of health care use are social networks; (4) social networks may influence the interactions with the care providers.

While the NEM does not negate the role of the individual as an active agent, it recognizes that social influences can be as equally, if not more important. For the purposes of the present study, we focused specifically on the ‘population characteristics’ and ‘informal networks’ domains of the NEM.
Theoretical Position

The theoretical approach underlying this study was that of relativist ontology, that is, previous *a priori* knowledge helped inform assumptions but allowed for emerging themes to arise (Patton, 1990). The paradigm guiding this research question was a naturalistic interpretive one. This multi-lens approach was concerned with understanding the subjective, complex, and contextual experiences of participants. The contextual and constructed realities of each participant helped inform and reshape knowledge gained from the research inquiry. Further, principles from Thorne’s interpretive description methodology facilitated the scientific inquiry, as this approach allowed for *a priori* assumptions (e.g., network episode theory) to be synthesized with knowledge gained from data, as well as other theoretical and contextual health services clinical knowledge.

Key informant recruitment

The recruitment strategy included purposeful snowball sampling for maximum variation in key informant experiences. We specifically aimed to have fair representation across gender, level of injury (cervical, thoracic, lumbar), and mechanism of injury (traumatic and non-traumatic), as well as socioeconomic status/funding source for health care services (private payments from motor vehicle accident compensation, public payment for services). We recruited from the community by advertising the study via the Canadian Paraplegic Association (CPA)-Ontario division’s website and email distribution. Semi-structured key informant interviews with community-dwelling individuals with a SCI provided the primary source of data. Key informants were at least 18 years of age as we focused specifically on adult experiences.
Informed Consent

Approval for this study was obtained from the University Health Network Research Ethics Board, as well as the University of Toronto. All participants provided informed consent prior to the interview.

Data Collection

Key informant interviews with participants were conducted using a semi-structured interview guide composed of a number of valid and reliable scales, open-ended questions and potential probes (see Table 3.1 for open-ended questions). Based on the NEM, a number of quantitative scales were used to describe socio-demographics and clinical characteristics of participants (items based on the Canadian Community Health Survey (CCHS, version 3.1)\(^\text{144}\) and the Ontario Spinal Cord Injury Registry (OSCIR)\(^\text{145}\), social networks (based on CCHS and the Arizona Social Support Interview Schedule (ASSIS)),\(^\text{103}\) and history of SHCs within the past year (Spinal Cord Injury Secondary Complications Scale (SCI-SCS)).\(^\text{146}\) The SCI-SCS was instrumental as a probe for detailed discussion related to how each of the identified SHCs was managed and the role informal networks played with these SHCs.

Quantitative Measures

Population Characteristics: Demographics and Clinical Characteristics

Demographic items included the following: age, sex, education, income, ethnicity, language, occupation, employment status, marital status, area of residence (urban/rural), and insurance source for medical care. Clinical characteristics included items such as level of injury, mechanism of injury, date of injury.
Formal care networks (e.g., physicians, rehabilitation professionals, and alternative medicine providers) were assessed using items from the CCHS. For example, “Not counting when you were an overnight patient, how many times have you seen or talked on the telephone, about your physical, emotional or mental health with... a family doctor... a specialist... a nurse... a physical therapist... a psychologist...”. Participants were asked to provide the initials of the care provider.

The Arizona Social Support Interview Schedule (ASSIS) is a semi-structured tool that consists of a series of questions that asks about a person’s perception of network size and the adequacy of the support received (i.e., satisfaction and need). In particular, the ASSIS measures six functional areas of social networks: (1) Material aid; (2) Physical assistance; (3) Intimate/private interaction; (4) Guidance; (5) Feedback, and (6) Negative social interaction. This tool allows for the following network properties to be measured: (a) network size (including available and utilized social networks), (b) network composition, (c) support satisfaction, (d) support need and (e) any sources of network conflict (see Appendix C). The ASSIS has shown good test-retest reliability for size of the available network with correlations ranging from 0.70 (over one month period) to 0.88 (over 2 or more days).

The survey starts with the following text: “In the next few minutes I would like to get an idea of the people who are important to you in a number of different ways. I will be reading descriptions of ways that people are often important to us. After I read each description, I will be asking you to give me the first names, the initials, or nicknames of the people who fit the description. These people might be friends, family members, teachers, priests, ministers,
doctors, or other people who you might know. If you have any questions about the descriptions I have read, please ask me to try to make it clearer.”

For each functional area, the following related to (1) size, (2) satisfaction, and (3) need were asked of a participant. For example, for the intimate interaction domain: (1) Size - “If you wanted to talk to someone about the things that are very personal and private, who would you talk to? Give me the first names, initials, or nicknames of people who you would talk to about things that are very personal and private”, (2) Satisfaction - “How would you rate your satisfaction or dissatisfaction with the times you talked to people about your personal and private feelings during the past month?” Response options include very dissatisfied, moderately dissatisfied, slightly dissatisfied, neither satisfied or dissatisfied, slightly satisfied, moderately satisfied, or very satisfied), and (3) Need - “During the past month, how much do you think you needed people to talk to about things that were very personal and private? Tell me which statement best describes your need, no need at all, slight need, moderate need, great need, or very great need.”

**Secondary Health Conditions**

The Spinal Cord Injury Secondary Complications Scale–Modified (SCI-SCS) is a 23-item measure of SHCs that impact health and physical functioning. Modified from the longer 40 item Secondary Complication Questionnaire (SCQ), the SCI-SCS was designed to measure complications related to skin, musculoskeletal, pain, and bowel/bladder. The measure uses a 4-point ordinal scale ranging from 0 (not experienced/insignificant problem never limiting activity) to 3 (significant/chronic problem). Items are summed and scores can range from 0 to 69, with the higher score reflecting greater problems with SHCs. The SCI-SCS has shown good convergent validity, internal consistency (>0.80), and test-retest reliability (>0.60).
Data Analysis

All key informant interviews were audio-recorded and transcribed verbatim. Data analysis used an iterative constant comparative process involving descriptive and interpretive analyses.\textsuperscript{108,109,111} Using a template analysis approach,\textsuperscript{148} a flexible coding structure was developed based on the NEM, which allowed for free nodes when emerging ideas or themes were identified. After each interview, the principal investigator (SG) wrote detailed reflexive notes on major emerging themes, which were later discussed in detail with one of the research investigators (SJ). The principal investigator (SG) coded all transcribed interviews. The other investigators (SJ, LLC, CC, TC and MM) independently reviewed a sample and compared emergent themes. Data management was facilitated using NVivo9 qualitative analysis computer software, as well as SPSS Version 19 for descriptive quantitative analyses.

RESULTS

Fourteen key informant interviews were conducted (6 men, 8 women). Demographics of the sample are shown in Table 3.2. The median age was 47.5 years (31-75). The median number of years post injury was 18 (range of 4-49 years). Approximately half of the participants had an injury at the level of the cervical spine (n=8). For mobility aids, approximately half of the participants used electrical wheelchairs (n=8), and the others used manual wheelchairs (n=6). Approximately a third of the participants had an education level of high school or less (n=4; 28.5%), associate’s degree or bachelor’s degree (n=5), or graduate level degree (n=5). Eight individuals lived with a spouse and/or common-law partner, and five people lived alone.

The majority of individuals (n=13) reported significant challenges with SHCs in the past year. In particular, significant or chronic problems were related to pressure sores, muscle spasms, and pain. Urinary tract infections were experienced in the last year for eight
participants, five of whom reported these infections to be moderate to significant problems. The mean score on the SCI-SCS was 15.3 (SD=8.2).

Composition of Social Networks

Overall Network Size

Using both the CCHS and ASSIS tools, the total network size was calculated. The median network size for participants was 16.5 (range 5-28), which includes family, friends, and health care providers. Table 3.3 shows the composition of networks by gender. Similar network compositions were identified for both males and females, with the exception of females having more friends comprise the informal networks (median=7.0 for females versus 4.5 for males).

Informal Networks

Participants are encouraged in the ASSIS to identify any formal and informal members that fit within the six domains. However, with the exception of four participants, individuals only identified family and/or friends rather than formal health care providers within their social networks for the six functional areas within the ASSIS. Specifically, only three individuals identified paid health care professionals as members of their networks within the functional areas of intimate/private as well as advice, and one individual identified the CPA within the advice network. All other participants only identified persons within their informal networks. Data analyses were conducted with both formal and informal networks; however, given the small number of health care providers identified in the ASSIS, the median values remained unchanged. Therefore, the following results will refer to only informal networks identified using the ASSIS.
Informal Available Networks

The overall median for available informal networks was 11.0 (range 3-19). Networks were larger for social support (median=6.5), and physical assistance (median=4.0), followed by positive feedback (median=3.5), advice (median=3.0), material assistance (median=2.5) and intimate relations (median=2.5; see Table 3.4).

Informal Utilized Networks

The size of utilized networks was considerably smaller than the available networks. Utilized network medians were largest for social support (median=5.5) and physical assistance (median=2.5). Only one participant reported using material assistance, the remaining sample did not use material support (median=0.0).

Perceived Satisfaction and Need

In all six functional areas, participants reported being very satisfied with their networks (medians=7.0; see Table 3.4). There was slightly more variation in perceptions of need, as median scores ranged from 1.0 (no need for material assistance) to 5.0 (great need for social support and physical assistance).

Shifting Networks Following SCI

The majority of individuals felt that their social networks decreased since their SCI, three individuals reported networks were moderately to significantly decreased, and four individuals felt that networks slightly decreased. Four individuals stated that their networks did not substantially change.
Thematic Results: Informal Social Network Roles

Numerous roles of informal networks were identified related to SHCs (see Figure 3.2).

Advice/Validating Concerns

Participants described how informal networks served as resources for advice related to SHCs, particularly with respect to validating concerns. Participants often spoke of uncertainty regarding the severity of a SHC and whether or not formal medical assessment/treatment would be warranted. In particular, informal networks often assisted individuals in clinical decision making of and self-management of SHCs.

“They’re the ones [wife and son] that sort of see me regularly and a lot of times I’ll just sort of go is it me or is it really a problem... So if there’s ever anything that’s sort of a concern or bothering me, I always sort of go to her [wife] first just because I know if I’m at the point where I’m squawking about something, there’s something wrong.” (Interview Male 011)

Knowledge Brokers

Participants described their informal networks as playing an integral role in the acquisition of knowledge related to prevention of and/or management of SHCs. Informal networks assisted individuals with researching and acquiring clinical information, seeking the appropriate health services, as well as facilitating knowledge exchange with various health care providers. Further, participants described how their informal networks acted as key players in facilitating linkages to health care professionals with appropriate expertise in managing SHCs.

“It was just by luck my wife knew a nurse through a friend of ours who was a bed sore nurse that travelled the world. She said ’let me take a look at the wound.’ She took a look at the wound. She offered this new product... and it cured me in 6 weeks. The doctor didn’t even know about this and he wanted to put me in the hospital for a month after the operation.” (Interview Male 013)

In particular, the Canadian Paraplegic Association (CPA) was mentioned by several participants as being a key lifeline for knowledge brokerage. For example, participants described
how the CPA provided individuals with a wide range of important information both directly and indirectly related to SHCs, such as self-management, community re-integration (work and volunteer opportunities, social opportunities), housing and personal support, community health resources and funding support (assistive devices and equipment, disability support).

“Like I said, CPA, if it hadn’t been for the regional coordinator, I would have been left slapping in the wind” (Interview Female 008)

Advocacy

Participants discussed how informal networks played a strong advocacy role, especially with respect to SHC management and ensuring that they received timely and appropriate care. Family members and friends often accompanied participants to medical appointments to assist with knowledge exchange and advocate if needed. Participants commonly reported a feeling that the medical community dismissed concerns related to SHCs and appreciated the advocacy role that informal networks played.

“I had an encounter with an orthopod who totally dismissed... I had a low energy fracture of the left tibia several years ago. I rolled over in bed and broke it and the first ortho that I saw he says 'there's no break there.' Meanwhile my leg is twice the size that it should be and bruised and hot and everything else. My sister actually pointed it out on the x-ray to him. ” (Interview Female 007)

Assisting with Finances

In addition, informal networks also assisted individuals in filling out lengthy documentation for equipment funding, such as financial support for pressure relief cushions, wheel chairs, home and vehicle modifications. The assistance with these applications was noted to be critically important, as access to assistive devices such a pressure relief cushions were essential in minimizing the occurrence of pressure sores. Participants described that the
applications for funding support were time consuming and complicated and informal networks provided substantial support in negotiating these funding processes.

Another important aspect to financial assistance is the personal financial contributions that informal networks provided. Many individuals described the financial “sacrifice” that their informal networks made, particularly family members, in order to minimize the occurrence of SHCs.

“I don’t reuse catheters. We [wife and participant] made a conscientious decision when this happened not to reuse catheters. We have the additional cost. Catheters are about $1 a pop… and I go through about 4 or 5 a day. It is a big cost and it’s not covered by insurance. But we said we will wear that cost not to go through the risk of urinary tract... But no issues that way but I think it’s because we’re being very proactive and a lot of people I know aren’t in a position where they can afford to sort of buy these things on a one use basis.” (Interview male A011)

Preventing SHCs

Participants were asked about their experiences with prevention and/or management of SHCs. With respect to facilitating prevention, participants described how informal networks assisted with important prevention behavior such as skin checks for pressure sores, swelling, bruises etc.

“I was sitting in a living room one day and I hadn’t really noticed any difference in the swelling of my feet. But my boyfriend did. He’s like ‘I don’t like the way your feet are looking, they’re really swollen for you.’ I looked down and it’s like oh yeah, I guess they are... So they can sometimes pick up things that you don’t and I think that’s extremely valuable... You get those that you trust to kind of do the areas that you can’t see and they get to a point where they might see something that you’re not aware of.” (Interview Female 007)
Managing SHCs

Participants indicated that informal networks provided significant assistance with managing SHCs. In addition, informal networks provide assistance in facilitating interactions with health care providers such as setting up medical appointments, transportation to and from medical appointments, as well as physical assistance in physically negotiating often poorly accessible medical offices/examination tables, as part of their role in managing SHCs.

“Especially for me because my biggest handicap… I can’t even push my hands to click a button or Bluetooth or anything. She [wife] has to do everything on the phone, answer it, deal with all the VHA and CCAC [Community Care Access Centre] and everything because it’s useless to hand it to me because she’s going to do all the follow up.” (Interview Male A013)

Informal networks provided substantial personal care with daily secondary complication management such as bladder and bowel care.

“... bowel regularity... My body works fine but it doesn’t work on a regular enough cycle...I always have to have somebody with me, either it’s to pull my pants down or to help maneuver the commode chair because it’s a little awkward. So I fundamentally have to work my bowel schedule around when I have somebody in the house to help me. So what I do is I now take basically it’s a suppository every two days and I have enough sensation I can tell if my bowels are getting full. So I can tell if there’s pressure... and literally I almost run my life around the bowel schedule...the two people that have to handle this with me is either my wife or my son. So I literally have to sort of okay what’s your schedule, where are you going, are you going to be in a meeting, just so I can make sure okay... it literally, it’s day one or it’s day two. If it’s day two, you come home. Now my wife fortunately works literally 10 minutes down the road from the house, so if all of a sudden I’m going I’ve got to go now, I often can just pick up the phone and say please come home now if you can. And she does...” (Interview Male A011)

Quality of Informal Network Relationships

Participants discussed the importance of their informal networks and the value that they placed on these relationships. Trust and flexibility were important characteristics of the
relationships with informal networks. With respect to trust, individuals described how informal networks provided support, both emotional and physical, in a safe environment.

“I think that you know a secondary team like the family and friends are just as important if not more so in some aspects of primary health care because the doctors, they see you briefly, they make the diagnosis. But then it’s the secondary team if you will that do the day to day things... You’re calling them at 3 am going help because you can’t get cleaned up or things like that and I think the secondary team is definitely not given enough credit... you’ve got the system and the team... you know, these are people that you trust that will go to bat for you, that will speak up for you and yet will allow you to be vulnerable. They just take what comes with the disability as it comes... they are a secondary team because they’re the ones that are doing the bowel cleanup, the catheters in the middle of the night, the dressing changes, skin checks. You see them every day whereas your healthcare practitioner you’re lucky if you see once every 3 months, something like that.” (Interview Female 007)

Participants described how the informal networks, in particular family members, always were on-call, available and adaptable in dealing with issues related to SHCs. These informal networks were described as members of a “secondary team”, critical in the prevention and management of SHCs. Finally, individuals described informal networks changing following their injury, usually becoming smaller but stronger networks.

“I found out who my friends were and who weren’t my friends or were just acquaintances. I think my network has become a closer network to me, a smaller group of people but closer.” (Interview Female 008)

**DISCUSSION**

**Size of Caregiving Networks**

In this descriptive exploratory mixed-methods study, we examined the structure, role and quality of networks of care for persons with a SCI using the NEM. We identified that individuals had an overall median informal and formal network size of 16.5 persons (range 5-28), which included health care professionals, community organizations, friends and family
members. In comparison to the general population, we identified that the size of overall networks for persons with SCI is slightly smaller, as networks in the general population range from 20-30 persons;\textsuperscript{149-151} however, similar to reported sizes of networks in similar vulnerable populations with disabilities such as mental health and rheumatoid arthritis (11.5 persons; 15.8 persons).\textsuperscript{150,152} In the general population, size of networks is important, as the larger a social network, the more likely information will be passed on and new contacts made.\textsuperscript{153,154}

Using the ASSIS, we identified the median number of available informal networks to be 11 persons (range 3-19). Specifically within intimate relations, participants had a median of 2.5 network members, which is smaller than the general population, as recently, Wellman and colleagues identified in the “Connected Lives Study”, persons living in Toronto felt “very close” to 4.1 network members.\textsuperscript{155} Social support and physical assistance networks were larger in size compared to the other four domains and participants rated these two domains in particular to be of “very great need”. Participants also reported using these social support and physical assistance networks more than the other domains.

\textit{Role and Quality of Relationships}

In addition to network size, we examined the role of network members as well as the quality of these relationships. This present study highlighted the importance of understanding the qualitative nature of social networks and the roles to which individuals play within the context of SHCs. While the size of the informal networks may be smaller than that of the general population, the close ties with informal networks described by participants in the qualitative interviews was evident. Specifically, bonding cohesive social capital, characterized by intimate relationships in which social and psychological support are provided to help with day to day care needs\textsuperscript{156} was prominent among participants rather than bridging social capital.
Bonding social capital is typically provided by relationships with family members as often these ties involve a significant amount of time with a strong intimacy and trust. Key players within the social support and physical assistance networks were often family members, particularly spouses and/or significant partners of participants. The latter type of social capital, bridging, is based on weaker ties which are better suited in providing instrumental resources (e.g., access to community services, knowledge diffusion) rather than emotional or physical support.

Previous research has identified the utility of bridging capital with the “strength of weak ties” and “structural holes,” that is, by increasing the number of non-redundant connections, individuals in theory have greater opportunity to access resources. However, in the present research, our qualitative data suggests that participants greatly valued a closer and stronger level of trust with their informal networks given the vulnerability of care provision potentially required. Participants described their informal networks as a “secondary team”, that is, a critical and essential force in dealing directly and indirectly with SHCs. The roles to which the secondary team members engaged in dealing with SHCs were identified as the following: (1) advice/validating concerns; (2) knowledge brokers; (3) advocacy; (4) assisting with finances; (5) preventing SHCs; and (6) managing SHCs. These results support the strength of cohesion, as strong ties are important when an individual is in a more vulnerable position and there is a need for trust and certainty. The roles identified of informal networks for persons with SCI are similar to informal care roles identified for persons with other chronic conditions. Recently, Essue and colleagues identified key roles in the self-management partnership for persons with complex chronic conditions (i.e., chronic heart failure, chronic obstructive pulmonary disease, and diabetes) to include: home helper, lifestyle coach, advocate, technical care manager, and health information interpreter.
This research suggests informal networks serve as essential key players in filling in the gaps that exist within the formal health care system. The gaps and barriers to health service delivery for those with complex chronic disabilities have been previously documented. Recently, Meade and colleagues specifically highlighted gaps in formal provider knowledge, provider-patient collaboration, quality of provider-patient communication, and discrimination for persons with SCI. Consistent with these findings, the present study identified that informal networks serve as central advocates, knowledge brokers and validate secondary complication concerns for persons with SCI.

This research highlighted that these small cohesive networks of close ties are indispensable for persons with a SCI. The reliance on these small caregiving networks highlights the vulnerability and fragility of the informal networks. Persons with SCI might benefit from a more expansive network rich with weak ties to access novel information and diverse resources (e.g., how to prevent SHCs, new technologies, how to apply for equipment funding). Developing and maintaining a larger diverse network with weaker ties may be unattainable for most people with SCI due to the constraints their condition imposes on their social life. Thus, given the complexity of the condition, persons with SCI may only have the time and effort to focus on very close relationships.

Further, despite the presence of these strong informal networks, the majority of individuals (n=13) reported significant challenges with SHCs in the past year. This raises concern as to what extent would persons with SCI be able to deal with SHCs if these informal networks were not available and/or be able to engage in the roles described in this research. Based on the present findings, individuals would likely be struggling significantly more to prevent and/or manage SHCs if only relying on the formal health care system. Importantly, there
is already significant strain on informal caregivers in assisting with supportive care for persons with SCI\textsuperscript{168-170} and this present research also highlights the extensive roles of informal care providers with SHCs.

In Ontario, there is a growing recognition of the importance of informal care provision in general, as exemplified by the Ministry of Health and Long-Term Care’s “Caring-About-Caregivers: Caregiving for the future of Ontario”.\textsuperscript{171} In this report, there is an acknowledgement of the need to support the social, health and economic well-being of informal care providers. For example, informal care provision affects participation in the workforce and the report recommends that employers offer flexibility and financial compensation for care provision (e.g., family leave). Given the critical roles assigned to informal care providers, it is pertinent that governmental organizations implement structures and policies that minimize the burden of care.

\textit{Limitations of the present research}

There are some limitations to this study. First, the ASSIS domains may have been too general for persons with SCI, given the complexity of the condition and the wide range of roles in which network members may serve. Given this, the qualitative data was critical to uncover the specific roles informal networks play in dealing with SHCs. For example, most participants did not recall any specific network member in assisting with material aid, however in the qualitative interviews, findings suggest that informal networks serve a key role in assisting with financial costs. There were several similarities between domains in the ASSIS and those that were identified from the qualitative data such as advice, social support, positive feedback (validation of concerns); however, the qualitative data identified some new items particularly related to process facilitation roles with more specificity to SCI, such as knowledge brokerage, and assisting with funding applications for durable medical equipment and assistive devices.
Future research in developing metrics on social capital for persons with disabilities may be warranted to explore whether these are common roles for informal care providers assisting those with any complex physical disability. For example, items might address informal caregivers’ time off work, costs associated with assistive devices, equipment, medical supplies, technology, transportation, and indirect health care costs not covered under public or private insurance plans. Finally, another limitation is that these results are based on a small sample of individuals with SCI and need to be considered in other settings. Specifically, persons with high ventilation tetraplegia or individuals requiring 24 hour care are underrepresented.

However, this research is useful as a foundation in understanding care networks and SHCs for persons with SCI. In using the NEM, understanding these networks of care and how they may relate to health care utilization and outcomes, recommendations to improve the management of care for the SCI population at the individual, provider and policy level can be made. Future research is warranted in examining other components of the NEM, specifically the health care environment/system, and how the components of the model interact in the journey of care for persons with SCI. Our research highlighted that while networks are smaller for persons with SCI, these ties are stronger, which is essential when the roles involve a level of trust, certainty, tacit knowledge, and flexibility. Indeed, these networks serve as a critical secondary team for persons with SCI.
<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>What have been your experiences with your health care in the community? &lt;br&gt; <em>Probes:</em> What made your health care experience easier? Harder?</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>What have been your experiences with care related to prevention and/or management of secondary complications? &lt;br&gt; <em>Probes:</em> What made it easier? Harder?</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>What has been the role of your informal social networks (friends/family) related to secondary complications?</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Is there anything else you would like to mention that we have not had the opportunity to discuss?</td>
<td></td>
</tr>
</tbody>
</table>

*Additional probes were used to facilitate discussion if needed such as “Can you tell me more about that? Can you speak more about the process? How so?”*
Table 3.2: Demographics of participants (n=14)

<table>
<thead>
<tr>
<th>Demographic/ Clinical Characteristic</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mechanism of Injury</strong></td>
<td></td>
</tr>
<tr>
<td>Traumatic SCI-Motor vehicle related</td>
<td>4</td>
</tr>
<tr>
<td>Traumatic SCI-Non motor vehicle related</td>
<td>7</td>
</tr>
<tr>
<td>Non-traumatic SCI</td>
<td>3</td>
</tr>
<tr>
<td><strong>Level of Injury</strong></td>
<td></td>
</tr>
<tr>
<td>Cervical</td>
<td>8</td>
</tr>
<tr>
<td>Thoracic</td>
<td>5</td>
</tr>
<tr>
<td>Lumbar</td>
<td>1</td>
</tr>
<tr>
<td><strong>Injury Severity</strong></td>
<td></td>
</tr>
<tr>
<td>Tetraplegia</td>
<td>8</td>
</tr>
<tr>
<td>Paraplegia</td>
<td>6</td>
</tr>
<tr>
<td><strong>Relationship Status</strong></td>
<td></td>
</tr>
<tr>
<td>Single/Divorced</td>
<td>4</td>
</tr>
<tr>
<td>Married/Common-Law</td>
<td>8</td>
</tr>
<tr>
<td>Dating</td>
<td>2</td>
</tr>
<tr>
<td><strong>Living Status</strong></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>5</td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td>8</td>
</tr>
<tr>
<td>Paid Attendant</td>
<td>1</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>1</td>
</tr>
<tr>
<td>High school</td>
<td>3</td>
</tr>
<tr>
<td>Associates degree/bachelor degree</td>
<td>5</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>4</td>
</tr>
<tr>
<td>Doctorate degree</td>
<td>1</td>
</tr>
<tr>
<td><strong>Family Income (includes spouse if applicable)</strong></td>
<td></td>
</tr>
<tr>
<td>Under 29,000</td>
<td>3</td>
</tr>
<tr>
<td>60-69,000</td>
<td>1</td>
</tr>
<tr>
<td>&gt;100,000</td>
<td>5</td>
</tr>
<tr>
<td>Declined</td>
<td>3</td>
</tr>
<tr>
<td><strong>Insurance Funding</strong></td>
<td></td>
</tr>
<tr>
<td>Motor Vehicle Insurance</td>
<td>2</td>
</tr>
<tr>
<td>Public Disability Support</td>
<td>8</td>
</tr>
<tr>
<td>None</td>
<td>4</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Return to work- yes</td>
<td>7</td>
</tr>
<tr>
<td>Return to work-no *</td>
<td>7</td>
</tr>
</tbody>
</table>

Reasons for not returning to work (n=7): 6 due to SHCs, 1 individual took early retirement
Table 3.3: Identified informal and formal networks by composition, family, friends, and health care providers (n=14)

<table>
<thead>
<tr>
<th>Gender</th>
<th>Family</th>
<th>Friends</th>
<th>Health Care Providers</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male Participants (n=6)</td>
<td>4.5</td>
<td>4.5</td>
<td>6.5</td>
<td>16.0</td>
</tr>
<tr>
<td>Female Participants (n=8)</td>
<td>4.5</td>
<td>7.0</td>
<td>6.0</td>
<td>17.0</td>
</tr>
<tr>
<td>Overall</td>
<td><strong>4.5</strong></td>
<td><strong>5.5</strong></td>
<td><strong>6.0</strong></td>
<td><strong>16.5</strong></td>
</tr>
</tbody>
</table>
Table 3.4: Informal network composition, satisfaction and need, based on the six ASSIS domains

<table>
<thead>
<tr>
<th></th>
<th>Available*</th>
<th>Used*</th>
<th>Satisfaction**</th>
<th>Need***</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intimate</td>
<td>2.5</td>
<td>1.0</td>
<td>7.0</td>
<td>3.0</td>
</tr>
<tr>
<td>Material</td>
<td>2.5</td>
<td>0.0</td>
<td>7.0(^+)</td>
<td>1.0</td>
</tr>
<tr>
<td>Advice</td>
<td>3.0</td>
<td>1.5</td>
<td>7.0</td>
<td>2.0</td>
</tr>
<tr>
<td>Positive Feedback</td>
<td>3.5</td>
<td>2.0</td>
<td>7.0</td>
<td>1.4</td>
</tr>
<tr>
<td>Physical Assistance</td>
<td>4.0</td>
<td>2.5</td>
<td>7.0</td>
<td>5.0</td>
</tr>
<tr>
<td>Social Support</td>
<td>6.5</td>
<td>5.5</td>
<td>7.0</td>
<td>5.0</td>
</tr>
<tr>
<td>Negative Feedback</td>
<td>0.0</td>
<td>0.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Median values are reported due to small numbers
**Ordinal scale, 1=very dissatisfied to 7=very satisfied
***Ordinal scale, 1=no need to 5=very great need
\(^+\) Only one person reported using material assistance
Figure 3.1: Conceptual framework based on Network Episode Model, with focus on population characteristics and networks of care for this study
Figure 3.2: Thematic results.

- Advice
- Advocacy
- Knowledge Brokers
- Assisting with Finances
- Preventing Complications
- Managing Complications

 quality of Relationship

- Trust
  - Safe
  - Validation
- Flexibility
  - On-call
  - Available
  - Adaptable
Abstract

Objective: To understand the journey of care in the prevention and management of secondary health conditions (SHCs) following spinal cord injury (SCI).

Methods: This was a case study design with “Ontario” as the case. The network episode model was used as the conceptual framework. Data sources included in depth interviews with persons with SCI, care providers, and policy and decision makers. Document analysis was also conducted on relevant materials and policies. Key informants were selected by purposeful sampling as well as snowball sampling to provide maximum variation. Data analysis was an iterative process and involved descriptive and interpretive analyses. A coding structure was developed based on the conceptual framework which allowed for free nodes when emerging ideas or themes were identified.

Results: Twenty-eight individuals were interviewed (14 persons with SCI and 14 persons representing care providers, community advocacy organization representatives, system service delivery administrators and policy makers). A major over-arching domain that emerged from the data was the concept of “fighting”. Eleven themes were identified: at the micro-individual level- (1) Social isolation and system abandonment, (2) Funding and equitable care, (3) Bounded freedom and self-management; at the meso care provider level- (4) gender and caregiving strain, (5) help versus disempowerment, (6) holistic care- thinking outside the box, (7) poor communication and coordination of care; and at the macro health system level- (8) fight for
access and availability, (9) models of care tensions, (10) private versus public tensions and (11) rigid rules and policies.

Conclusions: Findings suggest that the journey is challenging and a persistent uphill struggle for persons with SCI, care providers, and community-based advocates. If we are to make significant gains in minimizing the incidence and severity of SHCs, we need to tailor efforts at the health system level.
INTRODUCTION

A spinal cord injury (SCI) is a chronic condition that involves an insult to the spinal cord resulting in significant motor, sensory and/or bowel and bladder impairments. Advances in early acute care and rehabilitation have contributed to increased life expectancy and frequency of community discharge; however, these individuals continue to be at risk of serious secondary health conditions (SHCs). SHCs can include the following: respiratory disease, urinary tract infections (UTIs), heart disease, osteoporosis, overuse upper extremity injuries, sleep disorders, sexual disorders, suicides, pressure ulcers, chronic pain, fatigue, depression and/or respiratory infection. Despite the fact that many of these SHCs are potentially preventable, they are purported to be key contributors for ED visits, re-hospitalizations and/or death in the post-acute phase. Furthermore, SHCs continue to be problematic in approximately 20% of this population. Given the reduced lengths of inpatient rehabilitation, persons with SCI often require outpatient care to manage SHCs that have not stabilized at the time of index discharge. Indeed, this shift from inpatient care to community care has led to an increased role of formal care provision (paid medical professionals), as well as informal caregiving (unpaid providers such as family, friends, community organizations) to assist persons in the community. These high utilization rates of health care services suggest that care needs in the community are not being met for this population. Unmet care needs in primary health care, such as lack of information/education, psychosocial care, sexual and reproductive health, and health promotion have been previously identified in a few studies for persons with a SCI. Further, previous disability research has identified structural and process barriers in the community that influence the extent to which health care needs are met.
Structural and physical barriers relate to the access (e.g., inaccessibility of office facilities, transportation, diagnostic services) and availability (e.g., absence of services) of services; whereas process barriers are obstacles that an individual may encounter with the health service delivery process such as inadequate services (lack of lifts or transfer expertise), and fragmentation of services.45,46

Overall, there is a paucity of research that has examined unmet needs for persons with SCI living in the community,139 and in particular, very few that have examined factors related to the prevention and management of SHCs beyond the biomedical focus.179,180 Most of the research to date examining SHCs has been narrow in scope lacking the examination of broader social, community and environmental/health system factors,179 such as access, availability, satisfaction of service delivery, and social networks.180 These factors may play a role in the development of SHCs, health care utilization patterns, journey of care, and outcomes and warrant further investigation.179-181

In other vulnerable populations with high health care utilization, such as mental health, investigation of the social context has been useful in understanding the journey of care.60,72,73,97-100 In particular, Pescosolido’s (1991) Network Episode Model (NEM; see Figure 4.1) has been used as a conceptual guide in the mental health literature to understand the interactions at the micro level (individual), meso level (care networks), and macro level (health systems) with the overall journeys of health care (referred to as ‘illness career’ in Pescosolido’s model).79 The NEM has four dynamic domains, social context (sociodemographic characteristics or the organizational/health system constraints), social support system (informal networks), the treatment system (formal networks) and the illness career (journey of care). Networks of care are conceptualized by structure (e.g., size), content (strength of relationships, attributes of
relationship) and *functions* (the outcome of interaction such as advice, physical or emotional assistance, satisfaction with relationship).

Understanding these dynamic interconnected factors such as the structures and roles of care networks and their overall function are important, especially for populations that frequently interact with the health care system. Individuals who have suffered a SCI who are living in the community are one such population.

Currently, there is a gap in the literature pertaining understanding the journey of care related to SHCs for persons living in the community with a SCI. Most research has examined bio-medical variables (such as age, level of injury, mechanism of injury) as predictors of SHCs. There is a need to examine more contextual process-related factors to better understand the prevention and management of SHCs. Despite the relatively low prevalence of SCI, the burdens imposed on the individual, care providers, and health care system are significant as demonstrated by high health care utilization, decreased quality of life, and considerable financial costs. While we know that SHCs are likely influencing health care use, the paucity of research that has examined these issues in depth highlights that we have a poor understanding of what factors at the micro level (individual), meso level (care provider) and macro (health system) level, may be associated with SHCs development and persistence. There is a need to comprehensively examine the journey of care related to SHCs and factors related to their onset in a broader social context if any significant gains are to be made in minimizing their occurrence.

Therefore, in light of the importance of this topic, this paper sought to address the existing research gap by understanding the journey of care of persons with SCI related to SHC prevention and/or management. The primary objectives of this study were to describe the
journey of care related to the prevention and/or management of SHCs for community-dwelling persons with SCI and to understand factors at the micro (individual), meso (care provider) and macro (health system) level that may influence the journey of care.

METHODS

Case study design

A single exploratory case study design was used to understand the journey of care related to SHCs and the influence of informal and formal networks, health system and policies on this care. Case study design is ideal for understanding a phenomenon in complex detail and gaining insight into the contextual factors that may be related to the research question. For this research question, the province of Ontario was defined as the “case” under inquiry. The province of Ontario is situated in central Canada and has a population of approximately 13 million inhabitants.

Conceptual Framework

Pescosolido’s (1991) Network Episode Model (NEM; see Figure 1) was used to guide the research as this model acknowledges the interdependency and social context that exists between individuals and interactions with care providers and the health care system. The NEM has four interactive domains, social context (sociodemographics and organizational/health system constraints), social support system (informal networks), the treatment system (formal networks) and the illness career (hereafter referred to as journey of care). This model highlights the importance of community network structures, processes, and related functional outcomes as dynamic components that influence health behaviors and health outcomes.
Theoretical Position

The theoretical approach underlying this study was that of relativist ontology; that is, *a priori* knowledge helped inform assumptions but allowed for emerging themes to arise. The paradigm guiding this research question was a naturalistic interpretive one. This multi-lens approach was concerned with understanding the subjective, complex, and contextual experiences of participants, which consequently helped inform and reshape knowledge gained from the research inquiry. Further, principles from Thorne’s interpretive description methodology facilitated the scientific inquiry, as this approach allowed for *a priori* assumptions (e.g., network episode theory) to be synthesized with knowledge gained from data, as well as other theoretical and contextual health services clinical knowledge.

Key informant interviews

Semi-structured key informant interviews provided the primary source of data. Key informants included persons with a SCI living in the community, formal and informal care providers, case managers, administration/executive managers, policy-makers and decision makers. The recruitment strategy included purposeful snowball sampling for maximum variation in stakeholder experiences. In particular for persons with SCI, we specifically aimed to have fair representation across gender, level of injury (cervical, thoracic, lumbar), and mechanism of injury (traumatic and non-traumatic), as well as socioeconomic status/funding source for health care services (private payments from motor vehicle accident compensation, public payment for services). Key informant interviews were conducted in two phases. The first phase involved interviews with persons with a SCI recruited in the community by advertising the study via the Canadian Paraplegic Association (CPA)-Ontario division’s website and email distribution. The second phase of interviews involved formal and informal care providers, case managers, and
policy/decision makers. A preliminary list of key informants for this phase was developed by the research team and increased with snowball sampling techniques. In this second phase, key informants were those individuals with detailed knowledge of processes involved in managing SHCs for individuals with SCI.

**Document analysis**

In addition to key informant interviews, documents were reviewed to gain a better understanding of the health system context for individuals with SCI living in Ontario. These documents provided data to assist with comparing and contrasting data obtained from key informant data. Considerable efforts were made to review documents from multiple sources (gray literature, websites, and brochures). Participants were also invited to suggest any relevant documents that would help inform the research inquiry.

**Informed Consent**

Approval for this study was obtained from the University Health Network Research Ethics Board, as well as the University of Toronto. All participants provided informed consent prior to the interview.

**Data Collection**

**Phase I and Phase II**

Phase I interviews were conducted with persons with a SCI and Phase II with care providers, managers, policy-makers, and decision-makers. The interview process involved using open-ended questions and probes (see Tables 4.1 and 4.2 for open-ended questions). Due to geographical and potential accessibility limitations, the interviews were conducted over the telephone and audio-recorded. Phase I interviews ranged from 60 to 90 minutes in length and
the second phase ranged from 30-60 minutes in length. These interviews were conducted by telephone and audio recorded.

**Data Analysis**

All interviews were audio recorded and transcribed verbatim. Data analysis was an iterative constant comparative process involving descriptive and interpretive analyses. Using template analysis approach, a flexible coding structure was developed based on our conceptual framework (population characteristics, social networks, journey of care) which allowed for free nodes when emerging ideas or themes were identified. After each interview, the principal investigator (SG) wrote detailed reflexive notes on major emerging themes that were later discussed in detail with research investigator (SJ). The principal investigator (SG) coded all transcribed interviews. The other investigators (SJ, LLC, CC, TC and MM) independently reviewed a sample and compared emergent themes. Data management was facilitated using NVivo9 (QSR International, 2010) qualitative analysis computer software (see Appendix E for more detail on data analysis).

**Assurance of quality**

We followed Lincoln and Guba’s principles of trustworthiness as well as Yin’s validity guidelines for case methods. Theoretical saturation, constant comparative analysis, trustworthiness and validity checks provided assurance of data quality and rigor.

**RESULTS**

In Phase I, fourteen interviews were conducted with individuals who had a SCI (see Appendix D for more clinical characteristics). The majority of participants (n=13) identified having significant problems with SHCs in the past year. Fourteen participants were also interviewed in phase II (see Table 4.3 for stakeholder representation). These participants
represented the following categories, care providers, community advocacy organization representatives, system service delivery administrators and policy makers. Case documents were collected from the participants, community advocacy organizations (e.g. the Ontario Neurotrauma Foundation, Canadian Paraplegic Association-Ontario division) and various other websites (see Appendix E for a list of documents reviewed).

**Journey of care: A fight across the continuum**

A major over-arching domain that emerged from the data was the concept of “fighting” for all key stakeholder groups (e.g., between individuals with a SCI and the care providers; between individuals with a SCI and the health system, among care providers, and between care providers and the health system). Given this, the results will be structured within the context of the “fighting” and themes stratified by micro (individual-level), meso (care-provider level) and macro (health system level). In efforts to maintain participant anonymity, only gender (M or F), Phase I (A) or Phase II (B) and the broad stakeholder category will be included with each quote. Overall, eleven themes were identified and represented in Figure 4.2.

**Micro Level: Individual Experiences**

Three major themes emerged from the data that represented individual struggles/battles experienced by participants related to SHCs: (1) Social isolation and system abandonment, (2) Funding and equitable care, and (3) Bounded freedom for self-management.

**Social isolation and system abandonment**

Participants in both phases described several challenges in transitioning from inpatient rehabilitation to the community in dealing with SHCs. In particular, participants highlighted the issues with social isolation and spoke about a perception of system abandonment. Several
examples were described of individuals being discharged home prior to any home and/or vehicle modifications occurring, which posed increased risk for adverse events and SHCs.

“An individual that I was working with was really isolated. He was discharged to his home. The second story of his home was where the only bathroom was. So basically he was stuck on the second floor of his home with no way of getting down those stairs... I was very concerned about his safety and the very fact that if there was an emergency he would be at the mercy of the fire department to get him out. Anyway, because he was like in bed most of the time it took a couple of months for a physiotherapist. He was not in a position to be able to attend any kind of outreach, physical therapy opportunities. So yeah, it took like some time and he had a huge problem with edema.” (F-B001; community advocacy representative; informal care provider)

Participants in both phases spoke of the social isolation due to limited resources in more rural communities such as those in Northern Ontario. Recreational activities and community participation were noted as being important aspects of overall health and minimizing SHCs.

“...the lack of so many things that we all consider vital to our overall health and wellbeing, that the access and availability to it is so limited. I guess it’s again the social isolation that people face.” (F-B013; community advocacy representative)

In addition to rural areas, participants noted similar challenges with limited resources in suburban areas. Participants highlighted that unless they lived in an urban center with access to a specialized rehabilitation center for SCI, they were more likely to feel lost and disconnected.

The vulnerability of persons with SCI was evident and participants stressed the importance of feeling supported by their health care providers in dealing with SHCs. Participants in both phases spoke about the need to be easily connected with health care providers, especially given the acuity and sensitivity of some SHCs that can transition rapidly from a non-emergent scenario to an emergent situation. In particular, participants with SCI spoke about using the emergency departments as means to access primary care services due to various challenges in accessing a general practitioner.

“I did have one situation where I had a physician dump me as a patient and it was at a critical time from a mental health perspective... That can be much more devastating for
somebody who has a spinal cord injury and finds himself in a position where they don’t have a family physician, especially if you’re in kind of a crisis situation...” (M-A014; person with a SCI)

There was an added sense of social isolation if persons with SCI were not of the “typical” SCI, such as those with NTSCI. Participants spoke about research and supportive literature for SHCs being biased towards TSCI with limited resources for persons who might not fit the stereotypical pattern of a SCI. For example, participants spoke about the common perception that SCI is only traumatic and typically affects young males. This stereotyping can promote persons who might not fit in this stereotype to feel isolated in dealing with their SCI and associated SHCs.

“...the other gap I think is the non trauma... Trauma comes through a certain trajectory. You end up in an emergency, trauma send you up to acute care and you by and large end up in rehab... If you come out from oncology, you don’t and you are lost in the system... If you ... didn’t graduate from Toronto Rehab, you cannot get in without a GP referral and it depends when you have a GP and if you have a GP that has the time, energy and effort to sort of manage that piece for you...” (M-B004; senior system administrator)

On the other hand, the importance of community advocacy groups, like the CPA, was identified in minimizing social isolation, as these organizations helped link individuals to services within the community.

“...rehab is non-existent up here... There’s no follow up... CPA [Canadian Paraplegic Association], if it hadn’t been for the regional coordinator, I would have been left slapping in the wind.” (F-A013; person with a SCI)

**Fight for funding and equitable care**

Participants in both phases highlighted the inequities based on funding and insurance coverage. Inequities were suggested to be critical factors related to the prevention and/or management of SHCs. Particular differences were noted in community rehabilitation between those individuals with private insurance versus individuals solely relying on publically funded
rehabilitation such as home care services. Individuals with private insurance were able to receive private rehabilitation such as physical therapy, occupational therapy, massage therapy, while those individuals relying on home care services were not having needs addressed that would minimize the occurrence and progression of SHCs.

“...when I didn’t have insurance, there was like oh it’s ADP [Assistive Devices Program] so they’re going to get the bare minimum, so let’s get them in a chair. My chair was totally wrong for me when I got home, totally wrong... when I went to CPA, the regional coordinator kept looking at me and my chair going ‘you’re not sitting very well.’ She had somebody come and check it... I was practically laying down in my chair and she had it adjusted so that I could at least function until I could get a new chair... I remember the girl that was in the room with me, she had insurance and I didn’t and like she had tried out like 4 or 5 different chairs. I got like 2 to try and then they were pressuring me to order. The only reason I got 2 to try was because I didn’t like the first one. So like a really big difference and a lot of people will tell you that too. The care is totally different... If you don’t advocate for yourself, then you’re totally lost.” (F-A008; person with a SCI)

Participants in both phases highlighted the battles for individuals who did not have private insurance with respect to accessing proper technology and assistive devices, home and vehicle modifications, medical expenses for equipment such as catheters. One male participant spoke of the financial “sacrifice” that he and his wife consciously made to use new catheters every time to minimize the occurrence of urinary tract infections.

“She was very vulnerable. She was reusing catheters. ADP will give you a power chair but they won’t give you a manual backup. So if the power chair breaks, you’re stuck at home or stuck in bed. She will be able to purchase all of those services when she gets her settlement. So she’s going to go back into a house or a condo or something that is accessible. She will get a vehicle. She will be able to be mobile within her community. She will be able to manage her bladder better because she will have more attendant care and she won’t need to be reusing catheters. I mean the whole quality of her life is going to change as soon as this lawsuit is settled.” (F-B002, formal care provider)

The necessity for advocacy was noted whether it be driven by the person with the SCI, care provider, or advocacy group. The time required to negotiate the various processes and policies for funding such as assistive devices was ascribed to be similar to a full-time job.
“There’s a lot of negotiating, managing, working through, pulling out hair...” (M-A014; person with a SCI)

**Bounded freedom: The fight to self-manage**

Participants with SCI expressed frustrations at the care provider, as well as the health system level with respect to the concept of self-management. Persons with SCI spoke about having the self-efficacy to self-manage but highlighted that the health care system was paternalistic with barriers imposed on one’s ability to self-manage. For instance, participants spoke of not being able to initiate home care services without a general practitioner/family practitioner’s referral in circumstances when timely access is critical (e.g., wound management).

“The thing is he has to refer everything, so I have to go through my GP. Then it goes to CCAC [Community Care Access Centre/home care service], they have to approve it and they prioritize at CCAC. Then my ET nurse prioritized me though and then it goes to an agency and then with time restrictions for them, it took... it had been okayed at CCAC in two weeks and then it took another two weeks for the OT to come to me. So it had been sitting at the agency then...I’m top priority and I’ve waited a month... because my cushion needed checking and I was top priority for that and it took them over a month to get to me.” (F-A007; person with a SCI)

Some participants noted that their formal health care providers were not paternalistic in their interactions with patients, as there was a trust established with their formal health care providers to initiate needed care; rather, the larger health system is structured in a paternalistic manner with barriers at the system/policy level that prevented initiation of care.

“When I had this gash, I phoned up my family doctor and she’s superb. I’ve had her for 20 years and knows me on a first named basis. I sort of said ‘I’ve got this gash. I need somebody to come in and look at it.’ She sort of said ‘okay, try and do it yourself.’ Initially it was phone CCAC and see if you can do it yourself. Well their policy is you as the patient cannot initiate care unless you want to pay for it. It has to be done through a GP or what not. So it wound up being sort of a laggy process because my doctor doesn’t work 5 days a week, 8 hours a day... we wound up skipping through a weekend before we could get back on the phone to her and say ‘please make the phone calls to initiate this and this’ and it took a day or two to get that set up... I couldn’t get what I knew I needed fast enough... When the family doctor called, the earth moved. So it bothered me a little. Maybe it’s just me because I’m not the kind of person who tends to cry wolf. But you
know I clearly knew there was a problem and an issue, let’s just get it solved and let’s just get it solved and do it. I felt constrained by the system I guess.

(M-A011; person with a SCI)

**Meso Level: Caregiving Tensions**

Four major themes emerged from the data at the meso care provider level: (1) Gender and informal caregiving strain, (2) Help versus disempowerment, (3) Holistic care and thinking outside the box, and (4) Poor communication and coordination of care.

*Gender and informal caregiving strain*

The importance of informal caregiving was articulated by participants and often referred to as a “secondary team” and “filling in the gaps” of the formal health care system. In particular, women seemed to be providing more of the caregiving role, whether as a wife, mother, daughter or female friend.

“Her mother is elderly. When she dies I would imagine that she’ll probably have to be placed. She’ll go into long-term care. She’s very young. I don’t even know at this point if she’s eligible for senior housing and would probably cycle in and out of hospital as she ages and she starts to develop the chronic medical problems that we know that people with spinal cord injuries who have to function solely within the system do sustain.”

(F-B002; formal care provider)

Men who experienced an SCI seemed to be coping better in the prevention and management of SHCs as often their wives were performing on-call duties for activities such as bowel and bladder management. In contrast, women who were married or had a common-law relationship did not speak of their male significant others to be assisting with the more intimate personal care.

“Now my wife fortunately works literally 10 minutes down the road from the house, so if all of a sudden I’m going I’ve got to go now, I often can just pick up the phone and say please come home now if you can. And she does…”

(M-A011; person with a SCI)
Most participants in both phase I and II were aware of how dynamics between family and friends change with informal caregiving.

“...let’s go back to this same individual that spent that first year pretty much isolated in this small second story bedroom, that his wife was feeling overwhelmed because she actually maintained a full time job and she had minimal energy left at the end of the day to actually even clean her own house... the frustration because so many things are out of your control. That’s another part of this, whether it’s anything to do with systems or government or whatnot, is that feeling of being disempowered, when everything is out of your control, when you’re waiting by the phone so to speak for somebody to call and say ‘yes, it’s been approved.’... there’s a lot of caregiver burnout. Because you go to work, you come home and there are other things that need to be done. There’s more laundry, there’s incontinence issues.” (F-B001; community advocacy representative; informal care provider)

In particular, female participants with SCI spoke of being uncomfortable with these new role changes that occur with their informal care providers. There was a sense of frustration that they required help from informal care providers to help with day-to-day activities.

“Even with my family, I relied on them an awful lot but I didn’t want my mom to feel that she got her baby back. You know I was 40 some years old when this happened to me.” (F-A008; person with a SCI)

**Help versus disempowerment**

Participants in phase II spoke of the delicate balance between helping persons with SCI versus “over-prescription” and “disempowerment”. This balance was noted to be critical in maximizing independence and fostering a person with SCI’s ability to deal with SHCs.

Participants noted that there is a risk of over-prescription, particularly in the event that an individual with SCI has access to private insurance coverage, such as that from a motor vehicle accident.

“So they want to give everybody 24 hours of attendant care. Now if you actually receive 24 hours of attendant care when you don’t need it and you receive homemaking services and childcare services, all of a sudden there’s a question and there would be a question in my mind, is are we almost supporting a disability lifestyle. So there’s also a concern I know on the insurer part that over prescription in fact may promote a sense of greater
disability and a sense of needing help and a sense of becoming more and more dependent. Whereas I know in many cases attendant care is critical for toileting and dressing. There’s no question there’s a need for attendant care. But again, there’s a concern that it’s being over prescribed.” (F-B005; person with a SCI)

**Holistic care and thinking outside the box**

The findings highlighted perceptions of a struggle for validation and the necessity to continue “fighting” to have concerns heard by health care providers. Moreover, participants spoke of frustrations experienced with health care professionals primarily stemmed from the treatment of a SHC in a manner that fails to consider the “*whole person*” or context. Participants noted that treating a SHC with a silo narrow-minded lens led to a myriad of potential adverse risks.

“I think that doctors need to take a look at the whole person and how everything kind of fits together and how something like bladder and bowel problems can affect things like skin breakdown. They wanted to try different oral diabetic medications with me but most of them have diarrhea as a side effect. With a neurogenic bowel, that’s not the right way to go. But they don’t see that. They just see how these medications can help with the one disease or ailment that they are treating. They don’t see it as oh well, if it’s a neurogenic bowel, that means prone to diarrhea anyway, so you add a medication with the diarrhea as a side effect, that can lead to skin breakdowns, bladder infections, pressure sores. They don’t see it that way.” (F-A007; person with a SCI)

**Poor communication and care coordination**

Participants in both phases spoke about challenges with communication between persons who have a SCI, informal care providers and formal health care providers. Participants in phase II particularly noted that having access to a case coordinator made a significant difference in facilitating communication and care coordination. For example, several participants described how a private case coordinator is able to facilitate virtual rounds for all the formal health care professionals, informal care providers and the person with the SCI to discuss care management and SHCs.
“This is really kind of frustrating because when people don’t even know what they actually could be rightfully entitled to or what they could actually achieve... it’s so fortunate for the people that actually do have some kind of insurance coverage that at least quite often they will end up with a case manager or a lawyer or somebody that’s actually on their team. ...it’s a fight for everything... unless they have an unusual opportunity to have an ally or for example a wife or a parent or somebody that is just a go getter... But not everybody has that support... It’s a lot of connecting of the dots. When a person is depressed or having a bad pain day or whatever reason, that’s when they’re most vulnerable and that’s when they’re least capable of doing all this work, all this coordination. They don’t have the energy.” (F-B001; person with a SCI)

Despite the increased role of informal care providers and community advocates such as regional service coordinators with the CPA, many participants perceived a lack of respect for these individuals on the part of formal care providers and a failure to recognize them as an integral part of the team.

Macro Level: Health System Influences on the Journey of Care

At the health system level, four major themes emerged from the data: (1) Fight for access and availability, (2) Models of care tensions, (3) Private versus public tensions, and (4) Rigidity and inflexibility of policies.

**Fight for access and availability**

Participants in both phase I and phase II spoke about having to fight for access to services, particularly access to specialists (especially urologists) and rehabilitation professionals. In particular, participants noted significant wait-times for care, which was suggested to have exponential consequences for SHCs. As an example, several participants noted the lengthy wait-times for occupational therapy seating assessments. During this wait-time, participants spoke of pressure sores developing and causing a series of negative consequences including re-admission to the acute care. Re-admissions to acute care were required for several participants due to further wait-times to obtain access to community wound care management.
“...it’s just so promising to see all the research...And then when I think of coming back to [small town] and my community and what little there is for us and how long it takes individuals to actually get a referral to a urologist. I can give you an example of an individual that waited almost a year to see a urologist to get the results of urodynamics testing and then after all was said and done now he’s waiting another almost nine months for a referral to a urologist in the Toronto area. In the meantime he’s living life with ongoing incontinence issues and it’s really impacted the quality of life... It has far reaching systemic impact.” (F-B001; community advocacy representative; informal care provider)

In both phases, participants spoke of the challenges in physically accessing different health services in the community that are not in close proximity. Participant identified a need to have a “one stop shop” where all services would be in the same facility (diagnostic testing, screening services, specialists, general practitioners, rehabilitation professionals).

“... most of the people that I speak to with spinal cord injuries can’t get to their GPs because it’s not accessible. They can’t get on the examining bed.” (F-B002; formal care provider)

Models of care tensions

Models of care tensions were identified in four main areas: (1) biomedical versus social determinants; (2) prevention versus acute care; (3) GPs versus specialists; and (4) informal versus formal care provision. Participants noted that health is beyond the traditional bio-medical model and includes social determinants of health and preventative care. Participants spoke of frustrations with the narrow scope of publicly funded health care and noted that it is important to address the long-term well-being of a person in thinking about SHCs.

“Welfare and social assistance and all that needs to be considered because you’re looking at the person from a holistic point of view. You have to look at where they are in their life cycle and what are their needs and it’s not just healthcare. Other things contribute to probably their health deterioration... It’s health in its broadest sense, broadest term. So health and well-being fundamentally.” (F-B010; senior system administrator)
Models of care were seen to take a reactive approach that focuses on acute care following worsening of symptoms rather than a pro-active approach that focuses on prevention. The health system was consequently described as “putting out fires” (F-B001; community advocacy representative; informal care provider) rather than working on preventing SHCs.

“We don’t move money to the areas of high need. We react to the political pressures. Nor do we have a long run view. We have a short view... So what gets us through tomorrow or gets them out today, not what’s the best thing ultimately. You have to invest in that and I think prevention is a classic one. No one argues prevention. No one just wants to invest in it because it’s an opportunity cost against something today.” (M-B004; senior system administrator)

Participants in both phases also spoke of caregiving tensions surrounding the question of who should provide care to persons with SCI, in addition to the pros and cons of adopting different models of care in the process (specialist versus general practitioner, formal versus informal). The interviews reflected a lack of consensus among participants regarding who is best able to provide care. Several participants spoke about the responsibility of the formal system, particularly using general practitioners/family practitioners as the main source of care provision. Other participants suggested that SCI requires specialized knowledge, resources and time to which general practitioners/family practitioners do not have easy access. Given the specialized care that is often required when treating SCI, several participants highlighted the need for general practitioners to be supported by experts such as physiatrists.

“Most specifically with the healthcare is a lack of I guess awareness or lack of specialization on the parts of our local physicians about spinal cord injury and those secondary complications. Most physicians don’t have very much, if any, experience working with someone with a spinal cord injury. So I don’t think they understand those complications at all. As a result, they’re not able to effectively deal with those secondary complications or make appropriate referrals.” (F-B013; community advocacy representative)
There were also tensions regarding the increasing emphasis on informal care provision and decreasing responsibility of the formal providers. Several participants highlighted concerns with this growing shift in care delivery.

“Caregivers... they’re doing all the work. They’re doing themselves a service and a disservice. They’re servicing, they’re looking after a loved one. The problem is they’re masking the system’s inability to look after, so that they’re actually solving the problem so it isn’t a problem. They’re stretched to the limit to do that. As long as they can manage that piece one more time, then the system doesn’t... need to look after that individual because mom and dad are. In fact mom and dad are getting older, that the individual has no place to go when they pass on. That they can’t be caregivers to their parents is we don’t want to talk about that...” (M-B004; senior system administrator)

Participants in phase II noted that a case management model is useful in assisting individuals within the community deal with SHCs, and how case managers can appreciate the influence of the context in which an individual lives; however, differences were noted between private case management versus the publically funded model with home care services (to be discussed in more detail below).

**Public versus private tension**

Significant tensions were noted in the discussion related to publically versus privately funded care. Private insurance coverage, particularly within motor vehicle accidents, can provide individuals with significant financial protection compared to that of the publically funded health care. Several participants noted that this access to funds could lead to greed within the health care community and professionals with over-prescription. This notion of over-prescription in the privately funded community is a contrast to the significant struggles participants highlighted for basic services and equipment that are sought through publically funded channels. Participants in both phases noted the challenges of working within a multi-tiered healthcare system, particularly with community rehabilitation, which represents an important component for individuals with SCI.
“Well I think that there’s a general perception that Canada has a single tiered healthcare system and that’s simply not true and it’s unfortunate that people think that. I think it’s not so much the insurance sector. I think it’s the auto insurance sector where there are rich benefits for people who have spinal cord injury. So if you compare funds available to someone who sustains a spinal cord injury in a car crash versus someone who sustains spinal cord injury by a fall in their backyard, there’s a huge discrepancy… I think that because there are such rich accident benefits that are quite easy to access... they’re all fighting over a piece of the pie and nobody has to cure our patients. So they treat and treat and treat. I think there are a lot of good providers. I think there’s probably 25% or 50% of the system are really good people trying to do the right thing but the rest of the system is just trying to juice it. Of course the good providers get trapped in that whole game. Insurers become cynical and distrustful and they distrust the good provider just as they distrust the bad provider. Then there’s this misunderstanding and again, frustration, on all parts.” (F-B005; formal care provider)

**Rigidity and inflexibility of policies**

Participants in both phases noted frustrations with policies pertaining to initiation of health services particularly related to home care services. Previous frustrations are described in the “bounded freedom” theme with respect to policies requiring a physician’s referral to initiate services such as wound care or rehabilitation. In addition, participants noted frustrations with the rules established for determining rehabilitation eligibility. Participants with SCI commented on how being refused for rehabilitation led to increased risks for developing and/or worsening SHCs. These rules for rehabilitation eligibility were perceived by participants to highlight the “reactive” nature of health care rather than a focus on “prevention” and “maintenance of well-being”.

Participants in phase II also noted significant challenges with how family physicians and general practitioners are financially compensated. Most of these physicians are compensated by fee for service rather than salary-based compensation. As such, certain services that are not financially compensated (e.g., renewing prescriptions over the phone) require physicians to perform the service free-of-charge or individuals to physically visit the clinic.
“So how perverse is that? So that if I’m a family doctor, why would I take an hour for an individual when I’m compensated for 10 minutes?... Forget altruism. I mean it’s just unfair to make people do that. With that incentive system, take a whole bunch of people that don’t need healthcare or are they already well. So again, our models aren’t sweet enough to differentiate. It’s a one size fits all... I think that’s frustrating for individual families because they come out of it from that level. It’s about them. I mean it’s not about the policy. They’re saying I need these kinds of things to improve my quality and manage myself... So we over service some things and we under service other things.”

(M-B004; senior system administrator)

DISCUSSION

Using Pescolido’s NEM, we identified several key themes related to the journey of care for preventing and managing SHCs for persons with SCI living in Ontario. Specifically, we identified significant tensions and struggles that exist for persons with SCI, care providers, administrators and policy-makers. While these tensions were evident across the micro, meso and macro levels, these findings suggest that the structural and policy-related barriers within the macro health system are major obstacles in the care pathway (see Figure 4.3).

Taken together, the findings point to a general uphill journey for persons with SCI and for those who assist with care provision in the community. The individual struggles at the micro level were also highlighted, particularly with respect to perceived abandonment by the health system due to shortcomings with the provision of support and services, as well as various restrictions resulting from health care policies that are perceived to be strongly paternalistic in nature.182

These micro level battles seemed to be influenced by overall macro health system structures and rigid policies. Particular structural obstacles were identified that rendered pathways of care more arduous such as distribution of and access to services. Participants identified frustrations rising out of an inability to initiate care with the current gate-keeping referral model. These tensions reflect Lawn’s concept of “‘responsibilizing’ without power
sharing” (p.e7) and contributes to overall frustrating experiences with the health care system in dealing with SHCs, especially given most of the intervention efforts to date have been targeted to patient knowledge and self-management behaviors.\textsuperscript{48}

Further, given the current gate-keeping model of primary care and the vulnerability of persons with SCI developing SHCs, it is critical for persons with SCI to feel validated and concerns heard.\textsuperscript{167} The present study builds on previous work highlighting caregiving tensions between persons with SCI and care providers. Lack of formal care providers’ knowledge and negative attitudes\textsuperscript{46,47,167} seem to promote frustrating health care experiences for persons with SCI, and their informal care providers.

Additionally, participants noted rigid rules and policies within home care services that rendered significant difficulty in accessing \textit{“maintenance rehabilitation”}. Unless persons with SCI have access to private insurance and/or personal funds, community-based rehabilitation is limited in Ontario.\textsuperscript{183} Maintenance rehabilitation can serve an important role in preventing and/or slowing down the potential decline in functional ability; however emphasis is not placed on rehabilitation but rather acute medical needs.\textsuperscript{48} This is particularly important given the decreased length of stay in acute and rehabilitation facilities and earlier discharges to the community.\textsuperscript{48} It is beyond the scope of this paper to engage in a philosophical debate regarding what constitutes ‘rehabilitation’ but results of this study suggest that this discourse on rehabilitation and how we operationalize and implement the concept of rehabilitation warrants further attention.

The fight to access maintenance rehabilitation under the publicly funded health system highlights a significant weakness in its’ focus on acute bio-medical management rather than embracing a more individualized prevention chronic care and living well model. The lack of
rehabilitation services available within the publicly funded system once persons are discharged to the community was highlighted as a key barrier in preventing and managing SHCs.

The present research identified caregiving tensions with respect to who should be assisting with care and, in particular, the ambiguity of roles for informal care providers. We have transitioned responsibility to informal care providers without perhaps proper reflection of the ethics associated with this change of care delivery. Informal care providers and individuals associated with advocacy groups provide numerous roles as ‘secondary team members’ for persons with SCI (see paper 2). These secondary team members serve as critical allies in creating a more positive journey. However, as participants highlighted in the present research, at what point does the scale of informal-formal care provision become unbalanced? At what point is it no longer acceptable for informal care providers and community advocacy organizations to cover the fragmented holes in the formal health care system? As DeJong states “use of peer mentors, patient navigators, patient advocates, and other forms of patient coaching underscores many of the health system’s underlying weaknesses with respect to access, usability, and responsiveness” (p. 50).

This study stresses the importance of timely access to comprehensive primary health care. For certain conditions, such as pressure sores, persons with SCI need to have timely and efficient access to services from preventative services such as cushion assessments to wound management. In the present research, there were several examples of how long wait times ranging from occupational therapy assessment to community-based nursing care contributed to individuals with SCI being re-admitted to acute care facilities for wound management. While home care services in Ontario currently have a priority list, this research suggests that persons with SCI are not getting appropriate treatment in a timely manner that prevents the negative
sequence of adverse events for highly sensitive conditions. Due to rigid policies, participants with SCI in this study spoke of long wait times to see their GPs to initiate a home care service referral and then another delay in receiving home care services. The costs to the person as well as the health system are significant for pressure sore management. For example, the annual costs to home care services in Ontario (Community Care Access Centres, CCACs) for wound care management of approximately 30,000 persons is $240 million (CND).\textsuperscript{185} Specific to SCI, persons with pressure ulcer history have significant decrease in life expectancy\textsuperscript{186} and the cost to the system is estimated to be over $100,000 USD per pressure ulcer case in the acute care setting.\textsuperscript{187} A better triage priority system needs to be implemented across the continuum of care for persons with SCI in the community for these highly sensitive medical conditions.

Previous efforts to minimize SHCs have largely focused on the person with SCI and at the provider level.\textsuperscript{48} Results from this research suggest that in order to effectively reduce SHCs, we need to start thinking bigger and more holistically in addressing triggers of SHCs rather than fragmented efforts to “put out the fires”. Dejong recently noted three key solutions to improving health care for person with SCI in the community, (1) patient education and health behavior change, (2) better transitions from inpatient rehabilitation to community care, (3) new systems of health care delivery. Most efforts have previously focused the first solution\textsuperscript{48} and the present findings suggest that individuals with SCI are knowledgeable about their injury and SHCs; however, there seemed to be a need for improved knowledge dissemination as to how to navigate through the fragmented health care system. Documents reviewed for this study supported the notion that information on funding sources for durable medical equipment and assistive devices are not easily accessible to individuals. Informal care providers and community advocacy organizations (regional service coordinators within the CPA for example) were assisting as
knowledge brokers to address this challenge with knowledge transfer (see Paper 2 for more details).

Our research findings support DeJong’s second suggestion to improve transition to the community but especially to provide innovative new systems for health care delivery. The first and second solutions assume that that the community-based health system environment is agreeable to foster optimal care; however, the struggles identified in the present study suggest that we need to re-think the payment systems, delivery of services, and models of care.

Our current publicly funded health care system in Ontario, as exemplified by these findings, is a broken system for persons with SCI. Ontario policy-makers need to start innovatively thinking of strategies to minimize these barriers for persons with SCI living in the community. For example, perhaps there needs to be accountability and accreditation across the continuum of care. It is not acceptable for health care institutions or as Michael Porter calls “focused factories” to be working in silos with minimal feedback for care provision. We need to start thinking innovatively as to how best to provide timely, efficient, effective, comprehensive individualized care for persons with SCI and on a larger scale, for persons with any complex chronic condition.

It is our understanding, that to date, the NEM as presented in Chapter 1 (Figure 4.1) has not been applied beyond mental health and the present research has highlighted it is a useful model for other complex conditions, such as SCI. This model was useful in guiding the research inquiry, as it helped with the conceptualization of key areas related to the journey of care (e.g., network characteristics and environmental components). Based on the present research findings, a few modifications to the NEM are recommended in its application to understanding the journey of care related to SHCs for persons with SCI. A key modification would be to recognize the
magnitude of the health system and environmental influence on the overall journey, networks of care as well as the individual experience. Thus, the proposed change would be to place the other domains within the macro health system (see Figure 4.4), as this acknowledges the critical influence the health system environment has on the other domains.

**Limitations of research**

There are several limitations to this work that should be noted. Firstly, this research reflects the micro, meso and macro levels of Ontario as this province was selected for the case of inquiry. Given that health care services are provincially operated in Canada, these research findings may not be generalizable to these different contexts. Future research, such as a multiple case study, would be warranted in the examination of the journeys of care with other provinces. Comparisons of these case findings would be beneficial, especially in the context of different health system structures. As with all convenience sampling approaches, there is a potential for responder bias. However, considerable efforts were made to use purposeful sampling such that there was a broad representation across persons with SCI as well as the other stakeholder groups.

**Implications for future research**

This study highlighted several important themes, particularly with respect to health system and environmental factors that relate to the journey of care for SHCs. In using case study methodology and the NEM as a conceptual guide, findings from this study suggest the need for future research to investigate the associations between themes identified and health outcomes. Further, future research is warranted in examining more specifically how Porter’s outcome measures hierarchy framework fits within the context of SCI and SHCs.
Conclusions

This study focused on an in-depth examination of the journey of care related to SHCs for persons with SCI living in Ontario. Findings from this case-study suggest that the journey is challenging and an uphill struggle for persons with SCI, care providers, and community-based advocates. Results suggest that if we are to make significant gains in minimizing the incidence and severity of SHCs and improve the overall value of health care, we need to tailor innovative interventions at the health system level, rather than our current trend of fragmented interventions at the individual or health provider level.
Table 4.1: Phase I interview guide for open-ended questions with participants with SCI*

|   | What have been your experiences with your health care in the community?  
<table>
<thead>
<tr>
<th></th>
<th>*Probes: What made your health care experience easier? Harder?</th>
</tr>
</thead>
</table>
| 1 | What have been your experiences with care related to prevention and/or management of secondary complications?  
|   | *Probes: What made it easier? Harder? |
| 2 | What has been the role of your informal social networks (friends/family) related to secondary complications? |
| 3 | Is there anything else you would like to mention that we have not had the opportunity to discuss? |

*Additional probes were used to facilitate discussion if needed such as “*Can you tell me more about that? Can you speak more about the process? How so?”*
Table 4.2: Phase II interview guide for open-ended questions with care providers, managers, policy-makers*

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><em>Would you be able to tell me a little bit about your professional role?</em></td>
</tr>
<tr>
<td>2</td>
<td><em>What are some important barriers in preventing and/or managing secondary health conditions?</em></td>
</tr>
<tr>
<td>3</td>
<td><em>What are some facilitators in preventing and/or managing secondary health conditions?</em></td>
</tr>
<tr>
<td>4</td>
<td><em>What are some strategies and/or solutions that might help assist the prevention and/or management of secondary health conditions in the community?</em></td>
</tr>
</tbody>
</table>

*Additional probes were used to facilitate discussion if needed such as “Can you tell me more about that? Can you speak more about the process? How so?”*
Table 4.3: Participants by stakeholder involvement

<table>
<thead>
<tr>
<th>Stakeholder representation</th>
<th>Number*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Persons with SCI</strong></td>
<td></td>
</tr>
<tr>
<td>Traumatic SCI-Motor vehicle related</td>
<td>4</td>
</tr>
<tr>
<td>Traumatic SCI-Non motor vehicle related</td>
<td>7</td>
</tr>
<tr>
<td>Non-traumatic SCI</td>
<td>3</td>
</tr>
<tr>
<td><strong>Care providers</strong></td>
<td>10</td>
</tr>
<tr>
<td>Formal (physiatrist, GP/FP, PT, case managers)</td>
<td>9</td>
</tr>
<tr>
<td>Informal</td>
<td>1</td>
</tr>
<tr>
<td><strong>Community advocacy organization representatives</strong></td>
<td>6</td>
</tr>
<tr>
<td>Regional services coordinators</td>
<td>2</td>
</tr>
<tr>
<td>Senior administrators</td>
<td>4</td>
</tr>
<tr>
<td><strong>System service delivery administrators</strong></td>
<td>2</td>
</tr>
<tr>
<td>Public senior administrator and policy maker</td>
<td>1</td>
</tr>
<tr>
<td>Private senior administrator</td>
<td>1</td>
</tr>
</tbody>
</table>

*Numbers do not add to 28 because many participants represented multiple roles
SCI= Spinal cord injury
GP/FP= General practitioner/family practitioner
PT= Physical therapist
Figure 4.1: Conceptual framework based on Network Episode Model
Figure 4.2. Thematic results in conceptualization of the journey of care related to secondary health conditions
Figure 4.3: The uphill journey in the prevention and management of secondary health conditions

**Allies and Weapons**
- Advocacy and self-determination
- Secondary team - informal care network
- Improved communication/coordination
- Holistic and preventative care
- Access to resources and funding
- Technology and assistive devices

**Health System Barriers**
- Rigid “One-Size Fits All” policies (e.g. no self-referral)
- Gate-keeping model
- Ambiguity of roles
- Wait-times for services
- Biomedical focus
- Social inequities and funding
Figure 4.4: Revised Network Episode Model based on research findings
Chapter 5: DISCUSSION

The purpose of this chapter is to:

1) Summarize the three studies within this thesis
2) Discuss strengths and limitations of the work
3) Outline suggestions for future research of SHCs and SCI
4) Describe the implications of the thesis for persons with SCI, care providers, policymakers and researchers.

I. Contributions to the literature

The main purpose of the thesis was to understand the journey of care related to SHCs for persons with SCI living in the community. Collectively, findings from all three studies contribute to a better understanding of the journey and the unifying concept from these studies is that there is fragmentation of care in the community, which seems to contribute to the onset and progression of SHCs.

First, the patterns and characteristics of ED visits were examined at a population-based level. In this paper, we examined patterns of care (e.g., number of visits by year post injury) and characteristics of ED visits (e.g., acuity level, timing of visits, reasons for visits) made by persons with TSCI over a 6 year period following injury. We identified high rates of ED visits for several years following the initial TSCI. Given the nature of the injury, high health care utilization in the first year following injury is expected but our results show that individuals are still utilizing the ED at similar high rates many years following injury. Differences in ED patterns were observed based on the rurality index, as higher ED use was noted for individuals living in rural areas compared to those in more urban settings. This finding is consistent with
previous literature as access to and availability of primary care physicians are more challenged in rural than in urban centres.\textsuperscript{131}

Our results showed that regardless of acuity level, most individuals did not see a primary care physician on the day of the ED visit, despite the fact that the plurality of visits occurred during the weekday working hours. Particularly important for the 50\% of visits classified as potentially preventable and/or low acuity, primary care providers may have been able to address their health care needs rather than utilizing ED services. These findings should provide impetus for future research to examine the availability of and access to services in the primary health care setting in order to minimize potential inappropriate ED use. Additionally, future research might examine the decision-making process of persons with SCI in using the ED. This is the first study that has examined ED utilization patterns and characteristics for persons with TSCI over an extended time period. Given the high prevalence of SHCs, and the high rates of ED use for low acuity and potentially preventable conditions, these results suggest that the ED is being used as an inappropriate substitute for primary health care for individuals with TSCI. This study highlights that there are gaps at a population-based level in service delivery for the prevention and management of SHCs.

Second, we described the structure of informal caregiving networks, the quality of relationships, and the role these informal networks play in the prevention and management of SHCs. This study highlighted the importance of understanding the qualitative nature of social networks and the roles to which individuals play within the context of SHCs. While the size of the informal networks may be smaller than that of the general population, the close ties with informal networks described by participants was evident. Specifically, bonding cohesive social capital was prominent among participants rather than bridging social capital. Our data suggests
that participants greatly valued a closer and stronger level of trust with their informal networks given the vulnerability of care provision potentially required. This research highlighted that the small cohesive networks of close ties are indispensable for persons with a SCI. The reliance on these small caregiving networks highlights the vulnerability and fragility of the informal networks. Indeed, persons with SCI might benefit from a more expansive network rich with weak ties to access novel information and diverse resources (e.g., how to prevent SHCs, new technologies, how to apply for equipment funding). However, developing and maintaining a larger diverse network with weaker ties may be unattainable for most people with SCI due to the constraints their disability imposes on their social life. Thus, given the complexity of the condition, persons with SCI may only have the time and effort to focus on very close relationships. Participants described their informal networks as a “secondary team”, that is, a critical and essential force in dealing directly and indirectly with SHCs. The roles to which the secondary team members engaged in dealing with SHCs were identified as the following: (1) advice/validating concerns; (2) knowledge brokers; (3) advocacy; (4) assisting with finances; (5) preventing SHCs; and (6) managing SHCs.

Third, we identified significant tensions and struggles related to the journey of care and SHCs for persons with SCI, care providers, administrators and policy-makers. Our current publically funded health care system in Ontario, as exemplified by these findings, is a broken system for persons with SCI. Results suggest that if we are to make significant gains in minimizing the incidence and severity of SHCs and improve the overall value of health care, we need to tailor innovative interventions at the health system level, rather than our current trend of fragmented interventions at the individual or care provider level.
Use of a mixed method single exploratory case study design to understand the journey of care related to SHCs was ideal in allowing for a comprehensive analysis of health service delivery related to SHCs for persons with SCI in Ontario. Using a mixed-method approach, we were able to triangulate findings from the three studies which ranged from population-based data to individual contextual data. The first study examining patterns and characteristics of ED use highlights the scope of fragmented care delivery at a population level. It is clear from these findings that persons with SCI are not receiving appropriate primary health care services for a variety of factors. It is noteworthy that 50% of visits are for emergent/urgent visits. Findings from the second study suggest that informal care providers are assisting persons in accessing the ED for high acuity reasons. However, persons with SCI are likely not getting to the right place at the right time as exemplified by the rate of low acuity visits at the ED. The third paper builds on these findings and provides support that the way in which services are delivered in the community do not promote efficient and timely use of health services. Persons with SCI spoke about using ED services inappropriately due to access barriers in primary health care. Individuals acknowledged that using ED as a mechanism to address SHCs that could be managed by primary health care providers is a costly use of health services. However, given the time sensitive nature of certain SHCs, timely access is of urgency. Further, persons with SCI spoke of some uncertainty related to acuity level and the need for assistance in the decision-making process to assist them and their informal care providers in determining the most appropriate service provider.

The weaknesses of the formal health system place increased stress on informal care providers and community members. Informal care providers engage in critical roles as secondary team members to help enable a smoother journey for persons with SCI in the
prevention and management of SHCs. The roles that were highlighted in the second study of informal care providers are critical. Indeed, these “warriors” serve as essential key players in filling in the gaps that exist within the formal health care system. This raises concern as to what extent would persons with SCI be able to prevent and/or manage SHCs if these informal networks were not available and/or be able to engage in the roles described in this research. Indeed, the small cohesive ties highlight the fragility and vulnerability of these informal social networks. Based on the present findings, individuals would likely be struggling to prevent and/or manage SHCs if only relying on the formal health care system. There is already significant strain on informal caregivers in assisting with supportive care for persons with SCI and this present research also highlights the extensive roles of informal care providers with SHCs.

In study two, the roles identified of informal networks for persons with SCI are similar to informal care roles identified for persons with other chronic conditions. Recently, Essue and colleagues identified key roles in the self-management partnership for persons with complex chronic conditions (i.e., chronic heart failure, chronic obstructive pulmonary disease, and diabetes) to include: home helper, lifestyle coach, advocate, technical care manager, and health information interpreter. Further, similar to the present findings, Essue and colleagues noted that the informal caregiving relationship can create conflict between the care recipient, informal care providers, as well as the health care professionals. In the third study, significant caregiver tensions were identified related to the shift and ambiguity of these roles. Participants in the present research spoke of feeling frustrated that the necessity for informal caregiving to help with SHCs changed the dynamics of relationships.
Limitations of the research

There are a few methodological limitations to this research. One of the limitations of this research relates to the focus on the journey of care only in Ontario. Given the differences in service delivery across Canada as well as internationally, the extent to which findings can be generalized may be limited. However, efforts were made to ensure maximum variation in stakeholder experiences to address different needs for persons with a SCI such as injury level, funding source, gender, and residing community. Further, Ontario represents approximately 40% of the Canadian population. Building on the present thesis, future research would be helpful in using a multiple-case study design, with the other provinces in Canada being defined as separate cases.

A specific limitation first paper is related to the validity of the ambulatory care sensitive codes (ACSC). While the ACSC codes have been validated in the general population and for the geriatric population, these conditions have not been specifically validated in the context of TSCI as potentially preventable. Given the importance of understanding the role of primary care in the prevention and management of SHCs after TSCI this would be important future research. Also, due to limitations in available data, a longer-term follow-up was not possible (i.e., beyond six years).

In the second study, one of the potential limitations is that the six ASSIS domains (intimate interactions, material aid, advice, positive feedback, physical assistance and negative interactions) may have been too general for persons with SCI, given the complexity of the condition and the wide range of roles in which network members may serve. Given this, the qualitative data was critical to uncover the specific roles informal networks play in dealing with SHCs. For example, most participants did not recall any specific network member in assisting
with material aid, however in the qualitative interviews, data findings suggest that informal networks serve a key role in assisting with financial costs.

Finally, relevant for both the second and third study, a convenience sample with purposeful sampling strategy was used. This strategy can create a potential for responder bias. However, one of the advantages to case-methodology is the triangulation of multiple data sources. For example, we were able to triangulate the inappropriate ED use from our qualitative data with the population-based study using administrative data. Further, considerable efforts were made to use purposeful sampling such that there was a broad representation across persons with SCI as well as the other stakeholder groups.

It is our understanding, that to date, the NEM as presented in Chapter 1 (Figure 1.2) has not been applied beyond mental health and the present research has highlighted it is a useful model for other complex conditions, such as SCI. This model was useful in guiding the research inquiry, as it helped with the conceptualization of key areas related to the journey of care (e.g., network characteristics and environmental components). Based on the present research findings, a few modifications to the NEM are recommended in its application to understanding the journey of care related to SHCs for persons with SCI. A key modification would be to recognize the magnitude of the health system and environmental influence on the overall journey, networks of care as well as the individual experience. Thus, the proposed change would be to place the other domains within the macro health system (see Figure 5.1), as this acknowledges the critical influence the health system environment has on the other domains.
Future research

This thesis highlighted key areas for future research, which are described below:

1. Future research is suggested, using a multiple-case method, to examine how this revised conceptual NEM framework may apply in other provinces would be beneficial. Additionally, it would be useful to expand this revised framework beyond SCI to other populations with complex chronic conditions.

2. Future research in developing metrics on social capital for persons with SCI may also be warranted. For example, items might address informal caregivers’ time off work, costs associated with assistive devices, durable medical equipment, medical supplies, technology, transportation, and health care costs not covered under public or private insurance plans. Building on this, future work examining the extent to which social capital is associated with the onset and outcome of SHCs, associated health care utilization and quality of life would be helpful. Further inquiry on social capital in other complex conditions is warranted; for example, is bonding social capital also important for other complex chronic conditions?

3. Future studies examining the availability of services and access to primary health care services are needed to understand the reasons for the current pattern of preventable or low acuity ED visits. The current data suggest that only 50% of ED visits are likely appropriate given the acuity at time of presentation. There is a need to explore how comprehensive primary health care can be best provided to persons with SCI such that these inappropriate utilizations are minimized. How can we support our primary health care providers, such that services are provided in an equitable fashion, to not only the
patient, but also the service provider? Additionally, there is a need to examine ED patterns for persons with NTSCI. How do they compare with TSCI?

4. The present research highlighted significant tensions surrounding informal caregiving. Further inquiry related to the ethics of informal caregiving is warranted. Is it appropriate for health policies to shift responsibility to informal care providers? What implications does this shift have for persons with chronic conditions, informal care providers and their employers (if applicable), formal care providers, and not-for-profit community advocacy organizations?

5. More research is required on the concept of self-management and bounded freedom. Self-management programs are receiving significant attention from a health system funding and delivery perspective. The present findings suggest that there are negative consequences to individuals feeling confident in their self-management mastery but feeling restricted by policies in their abilities to engage in effective self-management behavior. Future mixed-method work would be useful in understanding the components of this bounded freedom and the potential psychological consequences to this perceived restriction. Beyond SCI, do persons with other complex chronic conditions experience this bounded freedom phenomenon in Ontario, in Canada and perhaps internationally?

6. Finally, we need to pilot innovative health care delivery interventions that aim to address the barriers identified in the present thesis. Future research needs to identify the most appropriate interventions. Based on this thesis some examples might include: (1) More timely access to: a) durable medical equipment and assistive devices (e.g., access to clean catheters, proper wheel-chair devices and cushions, pressure sore beds); b) medical and
rehabilitative care (24/7 phone consultation, priority triage access, autonomy for self-referral).

Implications

This study focused on an in-depth examination of the journey of care related to SHCs for persons with SCI living in Ontario. Findings from this case-study suggest that the journey is challenging and an uphill struggle for persons with SCI, care providers, and community-based advocates. We have a social responsibility to assist persons better in the community. Reducing health inequity and providing health services based on need has been emphasized by both the Romanow and Kirby reports.\(^{190}\) The Canada Health Act (CHA) mandates that each jurisdiction must provide access to medically necessary services;\(^{191}\) however, rehabilitation and ‘non-medically necessary’ community-based services do not fit within the scope of insured services.\(^{191,192}\) Given that we have placed an increasing shift to the community, Ontario policymakers need to start adopting some type of accountability across the continuum. It is not acceptable for health care institutions or as Porter calls “focused factories” to be working in silos with minimal feedback for care provision.\(^{188}\)

Indeed, the government of Ontario is attempting to increase accountability and improve quality of care, as exemplified by the recent law the ‘Excellence for All Act’ (ECFAA).\(^{193}\) As of June 2010, the ECFAA acknowledges that the patient should be made a priority and health care should be delivered with quality, value and best evidence. There are four guiding principles to this act, which include: (1) the focus of health care needs to be around the patient; (2) continuous quality improvement; (3) policy, planning and payment must support both the quality of health care and the efficient use of resources; and (4) quality care must be informed and supported by
best evidence and standards of care.\textsuperscript{193} Currently, it still remains unclear how exactly this EFCAA will impact overall primary health care and community services.

In recognizing the importance of care along the continuum and accountability, the Ministry of Health and Long-Term Care (MOHLTC) has developed in 2008 the “Strengthening Home Care Services in Ontario” strategy. As a deliverable to this strategy, the MOHLTC is implementing the Integrated Client Care Project, which is a multi-year pilot project aimed to achieve the best value of health care across the continuum. Based on Porter and Teisberg’s (2006) principles of value in health care\textsuperscript{194} and the concept of person/condition-centered bundled reimbursement, the goal is to link client groups to knowledgeable primary, acute and community sector specialized teams.\textsuperscript{195} There are five client groups identified for the initial phases of this project which include: wound care clients, palliative clients, frail elderly clients, clients with chronic disease, and medically complex children. While at early stages of pilot implementation for wound care, cost savings are expected to be significant with the overall goal of healthier Ontarians and increased sustainability of the health system across the continuum. For example, at full scale implementations for wound management, this bundled service approach is expected to have net annual savings of $100 to 200 million (CND) compared to usual care provision.\textsuperscript{185} Given the issues noted in the present research with fragmentation of care, bundled services might be of great benefit for persons with SCI. However, these bundled reimbursements would need to accommodate for the individuality of SCI and provide flexibility for care provision.

In addition to improving mechanisms of care for acute events once a SHC has occurred (i.e., wound care, urinary tract infections), we need to improve access to ongoing outpatient rehabilitation for persons with chronic conditions. Landry and colleagues identified that access to rehabilitation services in Ontario are based more on eligibility criteria rather than on
The rigid rules for rehabilitation eligibility often preclude persons from receiving preventative care and/or maintenance rehabilitation, which is important if we are trying to maintain functional status, prevent and/or minimize SHCs. Additionally, the eligibility for community services should also consider the needs of the informal care provider, and the relationship dynamics between the informal care provider and the care recipient. Similar to Canada, in Australia there is a growing acknowledgement of the challenges in access to community-based care and the burden informal care places on care providers. For instance, to assess eligibility for community care services, the Commonwealth Government’s Nationally Consistent Assessment includes “The Carer Eligibility and Needs Assessment-Revised” (CENA-R) questionnaire as one of the tools to measure carers’ needs and the impact of caregiving on the relationship with the care recipient. Ontario’s home care assessment process would benefit from such a tool that involves the care provider characteristics, as well as relationship attributes in determining eligibility.

Given that there is a growing trend to shift responsibility from formal care to informal care provision, findings from this thesis suggest that we might want to step back and think about the social implications of this shift in care. In 2009, the Ministry of Health and Long-Term Care have provided recommendations in their report on “Caring-About-Caregivers: Caregiving for the future of Ontario” to formally acknowledge the essential function of informal caregivers, and further identifies the need for increased supports to create a sustainable informal care provision environment. Key strategic themes included, (1) define ‘caregiver’ and provide protection for care recipients; (2) improve timely access to reliable caregiving information; (3) build employment protection and benefits for care providers; and (4) build and promote social networks for caregivers and provide liability protection.
The present research findings reiterate the importance of informal caregivers but cautions this increased emphasis on informal care. Our health care system in Canada is fundamentally based on universal equitable access. For persons with complex vulnerable needs, such as those with SCI, the care required is often specialized with significant demand. At what point do we as a socialize health care society, recognize that informal caregivers can no longer patch the weakness of the formal care system? What is the breaking point? What happens to persons with SCI or any complex chronic condition who do not have these secondary team members to make up for the gaps in formal care? The present research highlights the need to have a discourse on these relevant issues.

The present research highlight significant tensions with self-management and the restrictions participants felt with various policies that precluded persons with SCI and their care providers in their abilities to engage in self-management behavior. For instance, referral policies to initiate services such as home nursing care for wound management that require a physician’s referral can lead to a delay in the initiation of time-sensitive services. There needs to be better mechanisms to allow for persons to initiate these time sensitive services. Additionally, participants expressed significant frustrations with policies related to basic services provided by GPs that required individuals with SCI to physically visit with the physician, rather than capitalizing on technology. Basic items such as prescription refills and receiving laboratory results could be done via the telephone; however most physicians are not financially compensated with the Ontario Health Insurance Plan unless the individual physically visits the clinic. These remuneration policies need to be modified such that persons with complex conditions are able to receive health care services with minimal inconvenience and burden.
Finally, there are strategies that currently exist in Ontario enhance an individual’s ability to self-manage his/her attendant care that could be used as a model for other types of community care services. Funded by the MOHLTC and administered by the Centre for Independent Living in Toronto Inc., the direct funding program across Ontario allows for individuals to choose, schedule and train his/her attendants. Participants in this program receive a monthly allowance which is used for attendant care services up to 6 hours a day seven days a week. The concept of direct funding is helpful in thinking about ways in which we can empower individuals and care providers to self-manage with minimal barriers. Unfortunately, as noted by participants in the present study, there is a waiting list for this program and an arduous application process rendering this program inaccessible to most individuals. Further, what if an individual requires more than 6 hours a day of attendant care and how will an individual manage if there are no informal support systems in place to fill in these formal care system gaps?

Conclusions

These three studies demonstrate a better understanding of the journey of care related to SHCs for persons with SCI living in the community. There is fragmentation of care in the community which seems to contribute to the onset and progression of SHCs. Collectively, this research highlights that unless we provide more support to persons with SCI and their respective care providers, the trend of inappropriate health care use, morbidity and mortality related to SHCs will likely continue. Future research is necessary to examine how efforts at a macro health system level can assist with the journey of care with the goal of reducing SHCs and improving overall health and well-being.
Figure 5.1: Revised Network Episode Model based on research findings

![Diagram of Health System/Organizational Constraints, Informal Networks, Population Characteristics, Journey of Care, Formal Networks]
CANDIDATE’S ROLE

The candidate (SJTG) conceived the research questions addressed in this thesis, developed the study protocol with contributions from thesis committee members (Dr. Susan Jaglal, Dr. Louise Lemieux Charles, Dr. Tiziana Casciaro, Dr. Catherine Craven and Dr. Mary Ann McColl), supervised the recruitment of participants, conducted all interviews, supervised administrative data analyses for paper 1, performed data analyses for papers 2 and 3, and wrote the thesis manuscript.


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**Appendix A.**

**Table A.1 International Classification of Disease, Tenth Revision, Canada (ICD-10-CA), Diagnostic Codes for Ambulatory Sensitive Conditions**

<table>
<thead>
<tr>
<th>Condition</th>
<th>ICD-10-CA*</th>
<th>Exclude</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angina</td>
<td>I20, I23.82, I24.0, I24.8, I24.9</td>
<td><strong>Cases with surgical procedure</strong> <em>(CCI: 1,2,5)</em></td>
</tr>
<tr>
<td>Asthma</td>
<td>J45</td>
<td></td>
</tr>
<tr>
<td>Acute bronchitis*</td>
<td>J20</td>
<td></td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>J41, J42, J43, J44, J47</td>
<td></td>
</tr>
<tr>
<td>Congestive heart failure and pulmonary edema</td>
<td>I50, J81</td>
<td></td>
</tr>
<tr>
<td>Dehydration</td>
<td>E86</td>
<td></td>
</tr>
<tr>
<td>Gastroenteritis</td>
<td>K52</td>
<td></td>
</tr>
<tr>
<td>Grand mal seizure disorders</td>
<td>G40, G41</td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>I10.0, I10.1, I11</td>
<td><strong>Cases with surgical procedure</strong> <em>(CCI: 1.IJ.50, 1.IJ.57.GQ, 1.HZ.85, 1.IJ.76, 1.HB.53, 1.HD.53, 1.HZ.53, 1.HB.55, 1.HD.55, 1.HZ.55, 1.HB.54, 1.HD.54)</em></td>
</tr>
<tr>
<td>Hypoglycemia</td>
<td>E162</td>
<td></td>
</tr>
<tr>
<td>Kidney or urinary tract infection</td>
<td>N10, N151, N11, N136, N390</td>
<td></td>
</tr>
<tr>
<td>Pneumonia*</td>
<td>J12, J13, J14, J15, J16, J18</td>
<td></td>
</tr>
<tr>
<td>Severe ear, nose, or throat infection</td>
<td>J02, J03, J312</td>
<td></td>
</tr>
</tbody>
</table>

* ICD-10-CA = International Classification of Disease, Tenth Revision, Canada

*Only when a secondary diagnosis of chronic obstructive disease is present
## Appendix B.

### Figure B.1 Selection criteria

<table>
<thead>
<tr>
<th>Selection Criteria</th>
<th>Count (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICD-10 Codes from Rick Hansen Foundation between FY 2003-FY 2009</td>
<td><strong>1515</strong></td>
</tr>
<tr>
<td>Invalid value for gender</td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>&lt;18 years of age at time of admission</td>
<td><strong>88</strong></td>
</tr>
<tr>
<td>Previous hospital stay for SCI</td>
<td><strong>20</strong></td>
</tr>
<tr>
<td>SCI not most responsible diagnosis</td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>Died within index admission</td>
<td><strong>170</strong></td>
</tr>
<tr>
<td>Discharged after March 31, 2009</td>
<td><strong>12</strong></td>
</tr>
<tr>
<td>Repeat health records</td>
<td><strong>4</strong></td>
</tr>
<tr>
<td>1217 incident TSCI cases</td>
<td></td>
</tr>
</tbody>
</table>
Appendix C

Arizona Social Support Interview Schedule (ASSIS)

Revised/1988

*Materials for ASSIS obtained via personal communication with Dr. Manuel Barrera, Jr., Department of Psychology, Arizona State University, Email: Manuel.Barrera@asu.edu
Note: interviewer instructions are enclosed within parentheses. Responses should be recorded on ASSIS answer sheets.

(Read to participant):

In the next few minutes I would like to get an idea of the people who are important to you in a number of different ways. I will be reading descriptions of ways that people are often important to us. After I read each description, I will be asking you to give me the first names, the initials, or nicknames of the people who fit the description. These people might be friends, family members, teachers, priests, ministers, or other people who you might know. If you have any questions about the descriptions I have read, please ask me to try to make it clearer.

A. Intimate Interaction

A1. If you wanted to talk to someone about the things that are very personal and private, who would you talk to? Give me the first names, initials, or nicknames of people who you would talk to about things that are very personal and private.
(If the subject is unable to name a single person, go to A4).
(If the subject names one or more people, probe for any additional names by asking: is there anyone else you can think of?)

A2. During the last month, which of these people did you actually talk to about things that were personal and private?
(Inquire about people who were listed in response to A1, but who were not listed in response to A2.)

A3. How would you rate your satisfaction or dissatisfaction with the times you talked to people about your personal and private feelings during the past month?

1. very dissatisfied
2. moderately dissatisfied
3. slightly dissatisfied
4. neither satisfied or dissatisfied
5. slightly satisfied
6. moderately satisfied
7. very satisfied

A4. During the past month, how much do you think you needed people to talk to about things that were very personal and private?
Tell me which statement best describes your need.
1. no need at all
2. slight need
3. moderate need
4. great need
5. very great need
B. Material aid

B1. If you needed to borrow $25 or something valuable, who are the people you know who would loan or give you $25 or more, or would give you something (a physical object) that was valuable? You can name some of the same people that you named before if they fit this description, or you can name some other people.

(If the subject is unable to name a single person, go to B4.)

B2. During the past month, which of these people actually loaned or gave you some money over $25 or gave or loaned you some valuable object that you needed?

(If the subject names one or more people, probe for any additional names by asking: Is there anyone else you can think of?)

B3. During the past month, how satisfied or dissatisfied were you with the things that people loaned or gave to you?

1. very dissatisfied
2. moderately dissatisfied
3. slightly dissatisfied
4. neither satisfied or dissatisfied
5. slightly satisfied
6. moderately satisfied
7. very satisfied

B4. During the past month, how much you think you needed people who could loan or give you things that you needed?

Tell me which statement best describes your need.

1. no need at all
2. slight need
3. moderate need
4. great need
5. very great need

C. Advice

C1. Who would you go to if a situation came up when you needed some advice?

Remember, you can name some of the same people who you mentioned before, or you can name some new people.

(If the subject is unable to name a single person, go to C4.)

C2. During the past month, which of these people actually gave you some important advice?

(Inquire about people who were listed in response to C1, but who were not listed in response to C2.)

C3. During the past month, how satisfied or dissatisfied were you with the advice that you were given?

1. very dissatisfied
2. moderately dissatisfied
3. slightly dissatisfied
4. neither satisfied or dissatisfied
5. slightly satisfied
6. moderately satisfied
7. very satisfied
C4. During the past month, how much you think you needed to get advice?

Tell me which statement best describes your need.
1. no need at all
2. slight need
3. moderate need
4. great need
5. very great need

D. Positive feedback

D1. Who were the people who you could expect to let you know when they like your ideas or the things that you do? They might be people you mentioned before or new people.

(If the subject is unable to name a single person, go to D4.)

(If the subject names one or more people probe for any additional names by asking: Is there anyone else?)

D2. During the past month, which of these people actually let you know that they liked your ideas or the things that you did?
(Inquire about people who were listed in response to D1, but who were not listed in response to D2.)

D3. During the past month, how satisfied or dissatisfied were you with the times that people told you that they liked your ideas or the things that you did?

1. very dissatisfied
2. moderately dissatisfied
3. slightly dissatisfied
4. neither satisfied or dissatisfied
5. slightly satisfied
6. moderately satisfied
7. very satisfied

D4. During the past month, how much you think you needed to have people let you know when they liked your ideas or the things that you did?

Tell me which statement best describes your need.
1. no need at all
2. slight need
3. moderate need
4. great need
5. very great need

E. Physical assistance

E1. Who are the people who you could call on to give up some of their time and energy to help to take care of something that you needed to do--things like driving you someplace you needed to go, helping you do some work around the house, going to the store for you, and things like that? Remember, you might have listed these people before or they could be new names.

(If the subject is unable to name a single person, go to E4.)

(If the subject names one or more people, probe for any additional names by asking: Is there anyone else?)
E2. During the past month which of these people actually pitched in to help you do things that you needed some help with?

(Inquire about people who were listed in response to E1, but who were not listed in response to E2.)

E3. During the past month, how satisfied or dissatisfied were you with the help you received in doing these things that you needed to do?
1. very dissatisfied
2. moderately dissatisfied
3. slightly dissatisfied
4. neither satisfied or dissatisfied
5. slightly satisfied
6. moderately satisfied
7. very satisfied

E4. During the past month, how much did you feel you needed people who would pitch in to help you do things?
Tell me which statement best describes your need.
1. no need at all
2. slight need
3. moderate need
4. great need
5. very great need

F. Social participation

F1. Who are the people who you could get together with to have fun or to relax? These could be new names or ones you've listed before.
(If the subject is unable to name a single person, go to F4.)
(If the subject names one or more people, probe for any additional names by asking: Is there anyone else?)

F2. During the past month, which of these people did you actually get together with to have fun or to relax?
(Inquire about people who were listed in response to F1, but who were not listed in response to F2.)

F3. During the past month how satisfied or dissatisfied were you with the times that you got together with people just have fun and relax?
1. very dissatisfied
2. moderately dissatisfied
3. slightly dissatisfied
4. neither satisfied or dissatisfied
5. slightly satisfied
6. moderately satisfied
7. very satisfied

F4. How much do you think that you needed to get together with other people for fun and relaxation during the past month?
Tell me which statement best describes your need.
1. no need at all
2. slight need
3. moderate need
4. great need
5. very great need
G. Negative interactions

G1. Who are the people who you can expect to have some unpleasant disagreements with or people who you can expect to make you angry and upset? These could be new names or names you listed before. (If no one is identified, go to H.)

G2. During the past month, which these people actually had some unpleasant disagreements with you or actually made you angry and upset? (Inquire about people who were listed in response to G1, but who were not listed in response to G2.)

D. Personal characteristics of network members

Now I would like to get some information about the people you have just listed. (For each person on the list). Could you tell me:

Ha. What is this person's relationship to you?
### Appendix D

**Table D.1 Demographics of Participants with SCI (n=14)**

<table>
<thead>
<tr>
<th>Demographic/ Clinical Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mechanism of Injury</strong></td>
<td></td>
</tr>
<tr>
<td>Traumatic SCI-Motor vehicle related</td>
<td>4</td>
</tr>
<tr>
<td>Traumatic SCI-Non motor vehicle related</td>
<td>7</td>
</tr>
<tr>
<td>Non-traumatic SCI</td>
<td>3</td>
</tr>
<tr>
<td><strong>Level of Injury</strong></td>
<td></td>
</tr>
<tr>
<td>Cervical</td>
<td>8</td>
</tr>
<tr>
<td>Thoracic</td>
<td>5</td>
</tr>
<tr>
<td>Lumbar</td>
<td>1</td>
</tr>
<tr>
<td><strong>Injury Severity</strong></td>
<td></td>
</tr>
<tr>
<td>Tetraplegia</td>
<td>8</td>
</tr>
<tr>
<td>Paraplegia</td>
<td>6</td>
</tr>
<tr>
<td><strong>Relationship Status</strong></td>
<td></td>
</tr>
<tr>
<td>Single/Divorced</td>
<td>4</td>
</tr>
<tr>
<td>Married/Common-Law</td>
<td>8</td>
</tr>
<tr>
<td>Dating</td>
<td>2</td>
</tr>
<tr>
<td><strong>Living Status</strong></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>5</td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td>8</td>
</tr>
<tr>
<td>Paid Attendant</td>
<td>1</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>1</td>
</tr>
<tr>
<td>High school</td>
<td>3</td>
</tr>
<tr>
<td>Associates degree/bachelor degree</td>
<td>5</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>4</td>
</tr>
<tr>
<td>Doctorate degree</td>
<td>1</td>
</tr>
<tr>
<td><strong>Family Income (includes spouse if applicable)</strong></td>
<td></td>
</tr>
<tr>
<td>Under 29,000</td>
<td>3</td>
</tr>
<tr>
<td>60-69,000</td>
<td>1</td>
</tr>
<tr>
<td>&gt;100,000</td>
<td>5</td>
</tr>
<tr>
<td>Declined</td>
<td>3</td>
</tr>
<tr>
<td><strong>Insurance Funding</strong></td>
<td></td>
</tr>
<tr>
<td>Motor Vehicle Insurance</td>
<td>2</td>
</tr>
<tr>
<td>Public Disability Support</td>
<td>8</td>
</tr>
<tr>
<td>None</td>
<td>4</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Return to work- yes</td>
<td>7</td>
</tr>
<tr>
<td>Return to work-no *</td>
<td>7</td>
</tr>
</tbody>
</table>

Reasons for not returning to work (n=7): 6 due to SHCs, 1 individual took early retirement
Appendix E

Data Analysis

The theoretical approach underlying this study was that of relativist ontology; that is, *a priori* knowledge helped inform assumptions but allowed for emerging themes to arise.\(^\text{111}\) The paradigm guiding this research question was a naturalistic interpretive one. This multi-lens approach was concerned with understanding the subjective, complex, and contextual experiences of participants,\(^\text{112}\) which consequently helped inform and reshape knowledge gained from the research inquiry.\(^\text{113}\) Further, principles from Thorne’s interpretive description methodology facilitated the scientific inquiry, as this approach allowed for *a priori* assumptions (e.g., network episode theory) to be synthesized with knowledge gained from data, as well as other theoretical and contextual health services clinical knowledge.\(^\text{113}\)

All interviews were audio recorded and transcribed verbatim. Data analysis was an iterative constant comparative process involving descriptive and interpretive analyses.\(^\text{108,109,111}\) Analytical categories were developed using a template analysis approach,\(^\text{148}\) which allowed for a flexible coding structure. This approach allows for the identification of patterns and themes to emerge either deductively and/or inductively.\(^\text{148}\) An initial *a priori* coding template was developed based on the conceptual framework (population characteristics, social networks, journey of care) which allowed for free nodes when emerging ideas or themes were identified (see Table E.1). This coding template served as a guide for the emerging themes.\(^\text{148}\) As themes emerged inductively from the transcript analysis, a constant comparison process was employed such that each theme is compared systematically to the rest of the data.\(^\text{198}\)

After each interview, the principal investigator (SG) wrote detailed reflexive notes on major emerging themes that were later discussed in detail with research investigator (SJ).
principal investigator (SG) coded all transcribed interviews. After phase I interviews, research investigators (SJ, LLC, CC, TC and MM) independently reviewed a sample and compared emergent themes at the midpoint of the analysis (see Table E.2). The investigators reviewed and discussed these developing themes at an investigator meeting. Based on the emerging themes identified in Phase I, the investigators identified significant tensions and an overarching “fighting” concept throughout the themes. Based on these reflections, the principal investigator (SG) analysed the themes from both phases I and II together with the perspective of “fighting” and discussed in weekly meetings with research investigator (SJ). Themes were then organized into “micro”, “meso”, and “macro” categories based on the original NEM. Data management was facilitated using NVivo9 qualitative analysis computer software.

Assurance of quality

We followed Lincoln and Guba’s principles of trustworthiness as well as Yin’s validity guidelines for case methods. Trustworthiness involved four main components, (1) Credibility (checking transcripts, verifying themes with other key stakeholders); (2) Transferability (triangulation of results with the different data sources such as documents, different stakeholders); (3) Dependability (transparency of research and consistency of findings); and (4) Confirmability (preliminary research results were evaluated outside research team and the extent to which findings easily emerged from data). Preliminary findings were presented in several conferences and meetings with the audience being comprised of key stakeholders, and findings were well received in these settings. Additionally, two independent experts in case-methodology were consulted for external feedback regarding the methodology and data analysis. Therefore, theoretical saturation, constant comparative analysis, trustworthiness and validity checks provided assurance of data quality and rigor.
In efforts to maximize internal consistency and reliability, the interviews were audio-recorded and carried out by one investigator (SG). A single individual transcribed all the transcripts. As per case methods, multiple data sources (i.e., different stakeholders representing different roles/professions, documents, reports) were used to establish construct validity.\textsuperscript{108}

Table E.1: Initial template for themes based on the conceptual framework at start of analysis (2008)

<table>
<thead>
<tr>
<th>Population Characteristics &amp; Health System</th>
<th>Informal Networks</th>
<th>Formal Networks</th>
<th>Journey of Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical characteristics</td>
<td>Roles Function</td>
<td>Roles Function</td>
<td>Experiences with health care system related to SHCs</td>
</tr>
</tbody>
</table>
Table E.2: Themes emerging at midpoint of analysis (2009)

<table>
<thead>
<tr>
<th>Population Characteristics</th>
<th>Informal Networks</th>
<th>Formal Networks</th>
<th>Journey of Care</th>
<th>Health System</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Frustration</strong></td>
<td>Role</td>
<td>Holistic Care</td>
<td>Fragmented Fight/Uphill Battle</td>
<td>Funding Inequities</td>
</tr>
<tr>
<td>• Costs</td>
<td>• Knowledge Brokers</td>
<td>• Tensions not thinking outside box</td>
<td>Different journey if have: -secondary team helping to “fight” system</td>
<td>• Tension between private/public</td>
</tr>
<tr>
<td>• Challenges with access</td>
<td>• Prevention</td>
<td>• Narrow minded</td>
<td>-private funding</td>
<td>• Transportation</td>
</tr>
<tr>
<td>• Decreased autonomy, self-management challenges</td>
<td>• Management</td>
<td></td>
<td></td>
<td>• Access to equipment</td>
</tr>
<tr>
<td></td>
<td>• Emotional Support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Advocate</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Teemmate (warriors, advocates, fighters, push system)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Isolation</strong></td>
<td>Quality of relationship</td>
<td>Coordination of Care</td>
<td></td>
<td>Wait times</td>
</tr>
<tr>
<td>• Challenges with transition to community dealing with SHCs</td>
<td>TRUST</td>
<td>• Lack key player</td>
<td>• Especially to receive home care</td>
<td></td>
</tr>
<tr>
<td>• Uniqueness of injury, isolation if not typical SCI and dealing with SHCs</td>
<td>• Need for trust</td>
<td>• Challenges with referrals</td>
<td>• Increases severity of SHCs</td>
<td></td>
</tr>
<tr>
<td>• Fear of being alone managing SHCs</td>
<td>• Safe environment</td>
<td>• Significant wait times for essential services</td>
<td>• Wait to get referral and then to get specialist services</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Diffuse embarrassing situations</td>
<td></td>
<td></td>
<td>• Red tape, challenges with policies</td>
</tr>
<tr>
<td></td>
<td>• Validate concerns</td>
<td></td>
<td></td>
<td>• Tension with self-management models</td>
</tr>
<tr>
<td><strong>Mistrust</strong></td>
<td>ETHICAL TENSIONS</td>
<td>Communication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Mistrust in medical community regarding management</td>
<td>• Role strain</td>
<td>• Challenges with feeling validated by health care professional</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Mistrust with hidden costs of equipment</td>
<td>• Caregiver burden</td>
<td>• Challenges with knowledge transfer between professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• “Low ball” services if no private funding</td>
<td>• Uncertainly as to when to ask for help</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Personal Identity</strong></td>
<td>FLEXIBILITY</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Changed</td>
<td>• On-call</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>relationships with networks</td>
<td>Adaptability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participation in community (e.g. return to work bounded by funding structure of disability policies)</td>
<td>Adaptability</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**OVERALL TENSIONS**
- Shift roles
- Ambiguity of roles
- Self-management vs. formal health care system
- Time consuming managing SHCs
Appendix F.

Table F.1 Example list of documents collected and reviewed in Chapter 4 (Paper 3)

<table>
<thead>
<tr>
<th>Documents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canadian Paraplegic Association Websites</td>
</tr>
<tr>
<td>2010 Federal Disability Report</td>
</tr>
<tr>
<td>Community Care Access Center Website</td>
</tr>
<tr>
<td>Home and Vehicle Modification Program Guidelines</td>
</tr>
<tr>
<td>Ontario Travel Grants</td>
</tr>
<tr>
<td>Assistive Devices Program</td>
</tr>
<tr>
<td>Ontario Community Support Association</td>
</tr>
<tr>
<td>Centre for Independent Living Toronto</td>
</tr>
<tr>
<td>Financial Services Commission of Ontario: Auto Insurance</td>
</tr>
<tr>
<td>Slide decks from National Case Management Network</td>
</tr>
<tr>
<td>Codes of Ethics and Standards of Practice for Case Management</td>
</tr>
</tbody>
</table>