

2012-10-04

# Transitioning Through Middle Age with an Incomplete Spinal Cord Injury: A Qualitative Description of Changes in Physical Function: A Dissertation

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## Repository Citation

Armstrong, DK. Transitioning Through Middle Age with an Incomplete Spinal Cord Injury: A Qualitative Description of Changes in Physical Function: A Dissertation. (2012). University of Massachusetts Medical School. *Graduate School of Nursing Dissertations*. Paper 28. DOI: 10.13028/khcf-bt94. [https://escholarship.umassmed.edu/gsn\\_diss/28](https://escholarship.umassmed.edu/gsn_diss/28)

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TRANSITIONING THROUGH MIDDLE AGE  
WITH AN INCOMPLETE SPINAL CORD INJURY:  
A QUALITATIVE DESCRIPTION OF CHANGES IN PHYSICAL FUNCTION

A Dissertation Presented

By

DEBORAH K. ARMSTRONG

Submitted to the Graduate School of the  
University of Massachusetts Worcester in partial fulfillment  
Of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Nursing

August 2012

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University of Massachusetts Worcester

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*Transitioning through Middle Age with an Incomplete Spinal Cord Injury: A Qualitative  
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## Acknowledgements

This dissertation work would not have been completed without the guidance, patience, and support of many individuals. First and foremost, I am grateful to the participants who graciously shared their experiences. Each one of them contributed greatly to this research.

Great appreciation and thanks are given to my dissertation committee. Dr. Anne Kane, my dissertation chair, mentored and encouraged me through this process with tremendous grace. Dr. Susan Sullivan-Bolyai was a strong encouragement, and consistently offered her expertise and passion as a researcher. Dr. Faren Williams also encouraged me through this process, and provided wise guidance and assistance.

I am grateful for the support of the staff at the New England Regional Spinal Cord Injury Center at Boston Medical Center and the Greater Boston Chapter of the Spinal Cord Injury Association. Without their assistance in recruiting, I would not have had the opportunity to meet and learn from the study participants. I am also thankful for the support rendered by the Theta Kappa Chapter of Sigma Theta Tau for providing me with a small project grant for this research.

Special recognition and appreciation is given to my colleague, classmate, and friend, Dr. Elizabeth Chin, who has travelled this long road alongside me as the other half of the n of 2. She has spurred my learning in countless ways.

Completion of this dissertation and doctoral program would not have been possible without the constant encouragement, motivation, and loving support offered by my husband David. My daughters Patricia Muccitelli and Emily Bontemps provided much-needed support along the way, along with the two sons-in-law that they brought to our family during this process. I am grateful for the encouragement from my brother and sister-in-law, Stephen and Allison King, as well as from my entire Bethany Chapel family. Finally, I will forever be

humbled by the tremendous wisdom, incredible heritage, and unwavering practical support that I received from my parents, Drs. Paul and Patricia King.

I will praise thee, O Lord my God, with my whole heart;  
and I will glorify thy name for evermore.

Psalm 86:12

## Abstract

Over 260,000 Americans are living with a traumatic spinal cord injury (SCI). Medical advances have increased the longevity of individuals living with SCI into middle age and beyond. The majority of these individuals are living with an incomplete SCI (NSCISC, 2012), and the proportion of incomplete injuries is rising (DeVivo, 2012). There is little research that specifically examines the changes in physical function experienced by individuals aging with a traumatic incomplete SCI. The purpose of this qualitative descriptive study was to describe the changes in physical function experienced by participants with a traumatic incomplete SCI aging through middle age. Data were collected through moderately structured individual interviews (N=17), in either a face-to-face (n=6) or an email (n=11) format. The seventeen participants ranged in age from 35 to 65 years, with a 16 to 36 year duration of injury. Participants described changes in various body systems and recalled the timing of those changes as they transitioned through their middle years. Qualitative content analysis revealed that participants described primarily gradual changes including decreased muscle strength, decreased endurance, weight gain, and wear and tear changes. When asked to identify sources of information about physical changes, participants predominantly emphasized their lack of knowledge about anticipated changes. Further content analysis revealed three themes related to this transition. Participants likened their experience to *travelling through uncharted territory*. They described *strategies for living in uncharted territory* that help them to prevent or manage changes in physical function, with sub-themes of *being vigilant* in their self-assessment and self-management practices, investing time in *figuring out* what changes they experienced and why those changes happened, and *staying positive*. They also described the importance of *recognizing the impact of changes*. These findings provide a foundation for understanding this age-related transition, and identify

the need for further research to support effective self-management strategies and efficient mechanisms for disseminating this knowledge to people with SCI, their caregivers and families.

In acute and chronic patient care settings, nurses are well-positioned to be a valuable support and information source for individuals living with an incomplete SCI.



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## Chapter 1

### Problem Statement, Purpose, Aims, State of the Science and Significance

Traumatic spinal cord injury (SCI) persists as a significant threat to health in the US. There are approximately 12,000 new cases in the U.S. each year, and there are approximately 262,000 Americans presently living with SCI due to trauma (National Spinal Cord Injury Statistical Center [NSCISC], 2010). Medical advances in the last several decades have been credited with increasing the longevity of these individuals into middle age and beyond (Adkins, 2004; DeVivo, Krause & Lammertse, 1999; Kemp, Adkins & Thompson, 2004; Krause & Broderick, 2005; Krause & Coker, 2006). Traumatic SCI may be incomplete or complete, and individuals with incomplete injuries comprise about 60% of the population living with SCI.

Nurses and other health care providers play a vital role in the care of persons facing the challenges of traumatic incomplete SCI in the acute care setting and during post-injury rehabilitation, as well as throughout their subsequent life in community and primary care settings (Doloresco, 2008; Prescott, 2008; Starkweather, 2008). If health care providers are to effectively enhance the health of these individuals, we must increase our understanding of the changes in physical function they may experience as they age. Incomplete SCI's are complex and unpredictable, both in the acute stages and in later years (Gerhart, Charlifue & Weitzenkamp, 2000). There is a wide range of disabilities that can result from a traumatic incomplete SCI, and acute rehabilitation has generally focused on assisting the individual to maximize remaining neurologic function (Kemp et al., 2004). However, as this population lives longer, it is becoming clear that aging often brings an assortment of physical changes that exacerbate existing limitations and threaten hard-won independence (Hitzig et al., 2008; Kemp & Krause, 1999; Kemp et al., 2004; McColl, Stirling, Walker, Corey, & Wilkins, 1999; Price, Kendall, Amsters,



& Pershouse, 2004; Thompson & Yakura, 2001). A time frame of specific interest is middle age, defined as ages 40 to 60 for the purposes of this study. This time of life is characterized by a decline in physical function in the general population (Hitzig, Miller, Eng & Sakakibara, 2010; Timaras, 2007), and review of the literature indicates that the transition through the middle age years involves changes in physical function for individuals aging with a traumatic incomplete SCI (Charlifue, Lammertse, & Adkins, 2004; Hitzig et al., 2008; Kemp et al., 2004; Krause, 2007; McColl, Charlifue, Glass, Savic & Meehan, 2002; Menter, 1992; Price et al., 2004; Thompson & Yakura, 2001).

Developing a clearly articulated body of knowledge about the range of experiences of aging through middle age with a traumatic incomplete SCI will enable effective nursing practice and provide important information to develop future educational interventions to support this patient population. The identification of specific changes in physical function experienced by these individuals is one key aspect of understanding the multidimensional aging process.

Therefore, the purpose of this qualitative descriptive (QD) study was to describe the changes in physical function experienced by participants aging through middle age with a traumatic incomplete spinal cord injury from their own perspective. The specific aims of this study were to:

1. Explore any changes in physical function identified by participants as they experience aging through the middle years with an incomplete SCI.
2. Describe the participants' awareness of the timing of these changes in physical function, and any critical events they associated with the changes they identified.

3. Describe the participants' engagement in the transition, in terms of anticipatory knowledge and preparation for any changes in physical function they have experienced as they age, including their past or present sources of information for that knowledge.

Gaining a rich description of the physical changes people with a traumatic incomplete SCI experience as they go through middle age provides important information to persons with traumatic incomplete SCI, their families, and their healthcare providers. In addition, this description can support eventual intervention research, testing strategies that can help these patients, families and providers collaborate to prevent some loss of function and plan for unavoidable changes associated with the transition of aging (Krause & Coker, 2006).

### **State of the Science**

While the average life expectancy in the United States has increased by approximately thirty-five percent since 1940, the average post-injury life expectancy for individuals with SCI has risen by almost two thousand percent (Adkins, 2001). Approximately forty percent of persons living with a traumatic spinal cord injury are currently over the age of forty-five, and at least twenty-five percent of these individuals have lived with their SCI for over twenty years (Cristian, 2004; NSCISC, 2010; Weinel, 2005). In response to these changing demographics, there is a growing body of multidisciplinary research that examines various aspects of aging with a SCI (Charlifue, 2007; Hitzig, et al., 2010; Kalpakjian, Quint, Bushnik, Rodriguez & Terrill, 2010; Kemp et al., 2004; Krause & Broderick, 2005; Liem, McColl, King & Smith, 2004; Wiley, 2003).

### **Classifications of SCI**

SCI can be categorized into two subgroups based upon etiology: traumatic and nontraumatic. According to the NSCISC (2010), the most prevalent causes of traumatic SCI in

the United States are motor vehicle accidents (41.3%) and falls (27.3%). Gunshot wounds and other acts of violence currently account for 15% of traumatic SCI, a decline from the 1990's, when SCI due to acts of violence peaked at 24.8%. Another declining but significant etiology is sports-related injury, which presently accounts for 7.9% of traumatic SCI. Across all etiologies, 80% of traumatic SCI's occur in males (NSCISC, 2010).

Nontraumatic SCI occurs secondary to a wide variety of etiologies, including congenital conditions such as spina bifida, primary and metastatic tumors, multiple sclerosis and other inflammatory and/or infectious conditions, degeneration of the spinal column with central nervous system impingement, and vascular pathologies such as spinal artery thrombosis or arteriovenous malformations (Guilcher et al., 2010; McDonald & Sadowsky, 2002; New, Rawicki & Bailey, 2002; New & Sundararajan, 2008). Because of the vast number of etiologies, as well as a lack of federal or state registries tracking individuals with non-traumatic SCI, there is only limited information regarding the incidence and prevalence of nontraumatic SCI (McDonald & Sadowsky, 2002; New et al., 2002; New & Sundararajan, 2008), and the majority of the research literature regarding SCI is specific to traumatic injuries (Guilcher et al., 2010; New & Sundararajan, 2008; Ones, Yilmaz, Beydogan, Gultekin & Calgar, 2007). Recent demographic data indicates that nontraumatic SCI occurs in a significantly older population with more co-morbidities than those incurring traumatic SCI (Guilcher et al., 2010). Comparisons of persons with nontraumatic SCI and traumatic SCI indicate the need to explore these as two distinct populations (New et al., 2002; Ones et al., 2007).

In addition to the etiological classifications, SCI is often broadly categorized by level of injury. The term *tetraplegia* describes injuries that occur in the cervical segments of the spinal cord, causing impairment of motor and/or sensory function in the arms, trunk, pelvic organs and

legs, while in *paraplegia*, arm function is preserved (Maynard et al., 1997; Young, 2008). Another broad classification of SCI reflects the completeness of injury. A SCI is defined as *complete* when there is a lack of sensory and motor function below the level of injury. This definition is operationalized by determining that there is no sensory or motor function at the lowest sacral segment, which innervates the perineal and anal region (American Spinal Injury Association [ASIA], 2006; Young, 2008). Complete injuries are designated as ASIA Impairment Scale (AIS) A. An *incomplete* injury includes some preservation of sensory and/or motor function below the neurologic level of injury (Maynard et al., 1997). Incomplete injuries are further categorized based upon the grading of muscle function. Individuals with AIS B grade injuries have preservation of sensory function below the level of neurologic injury, but lack motor function. AIS grades C and D are often coupled under the term “motor incomplete.” Persons with these injuries have some degree of motor function below the level of neurologic injury (ASIA, 2006), which may include the ability to ambulate (Saraf et al., 2010; Wirz et al., 2005). Persons who recover full sensory and motor function following SCI are classified as AIS E (ASIA, 2006). Appendix A contains the standardized worksheet developed by ASIA for classifying SCI.

### **Incomplete SCI**

A significant portion of the SCI population is made up of individuals living with incomplete injuries. Since 2000, approximately 53% of new traumatic SCI's are designated as incomplete tetraplegia (38.3%) or incomplete paraplegia (21.5%) (NSCISC, 2010). According to NSCISC estimates based upon several research studies, there are approximately 6,400 people who sustain new traumatic incomplete SCI's per year in the United States, joining the 137,000

people already living with incomplete SCI. The estimated numbers of incidence and prevalence have risen gradually over the years since the initial report of the NSCISC (NSCISC, 1994).

Individuals with traumatic incomplete SCI comprise a unique population. The literature suggests that they share some characteristics with persons with complete SCI (Drake, Cortina-Borja, Savic, Charlifue & Gardner, 2005; Ku et al., 2005) and diverge in other areas (Bauman, Adkins, Spungen, Kemp & Waters, 1998; Kemp, Adkins & Thompson, 2004; Linn, Adkins, Gong & Waters, 2000). Thus, the experience of aging with an incomplete SCI due to trauma must be examined as a unique experience.

### **Review of the Literature**

This section presents a review of the literature on the topic of aging with an incomplete SCI. First, the broad concept of aging is addressed, followed by a brief discussion of aging with a SCI, with specific emphasis given to biological aspects of aging and the associated changes in physical function. Finally, the literature addressing changes in physical function experienced as individuals age with an incomplete SCI is reviewed.

#### **Aging**

Aging is a natural, inevitable, and progressive process (Aldwin & Gilner, 2004; Austad, 2001; Hitzig et al., 2010; Kemp et al., 2004, Timiras, 2007). In the broadest sense, aging is what happens to an individual as times passes. This definition would include the passage of time without change, beneficial changes over time, and changes associated with deterioration or loss over time (Austad, 2001). Aging is multi-dimensional, including psychological, social, and physical changes (Aldwin & Gilmer, 2004; McColl et al., 2002; Menter, 1992; Pentland et al., 2002). Theoretically speaking, various philosophical perspectives suggest its vast scope.

Gaining an understanding of the complexities of aging has in fact been identified as one of the greatest challenges facing scientists in the 21<sup>st</sup> century (Aldwin & Gilmer, 2004).

Aging is distinct from the state of being aged. One of the challenges to the study of aging is the lack of a clear marker for the beginning of aging. Many scientists identify the onset of aging as the time when body systems reach their peak capacity in early adulthood (Hitzig et al., 2010; Kemp et al., 2004; Austad, 2001; Weinel, 2005). Not only is the onset of aging ambiguous, but there is no single, chronological timetable for aging as it progresses (National Institute on Aging [NIA], 2008). Arbitrary designations are often used to describe divisions or stages in the human lifespan (Davis & Friedrich, 2010). Of particular interest for this study is the period of time commonly referred to as *middle age*. Middle age is the time between youth and old age (<http://wordnetweb.princeton.edu/perl/webwn?s=middle%20age>), but specific operational definitions vary. A review of frequently used web sites indicated that “middle age” in common parlance can refer to a variety of age ranges, generally starting at 35 to 40 and ending at 55 to 60 years of age. Based on the seminal work of developmental scientist Erik Erikson, Levinson (1986) proposed a conception of adult development that identified a mid-life transition at age 40 to 45. This ushers in the “era of middle adulthood” (p.8) which lasts until age 60. A recent study on aging stereotypes which addressed physical and psychosocial domains of aging classified 40 to 49-year-olds as “young middle age” and 50 to 59-year-olds as “older middle age” (Davis & Friedrich, 2010).

Without doubt, the ambiguity that characterizes the specific definitions of aging and middle age is due to multiple perspectives, as well as the fact that how an individual ages is affected by an array of physical, environmental and social factors (Aldwin & Gilmer, 2004;

Masoro, 2006; Timiras, 2007). One factor that impacts the aging trajectory is the presence of a physical impairment or disability such as the effects of SCI (Hitzig et al., 2010; Putnam, 2002).

### **Aging with a SCI**

There is a significant body of knowledge developing across many disciplines on the topic of aging with a SCI (Hitzig et al., 2010; Kemp et al., 2004; Krause & Broderick, 2005). Many authors and researchers have identified a complex interplay between aging and SCI (Charlifue et al., 2004; Kemp et al., 2004; Krause, 2007; McColl et al., 2002; Menter, 1992; Thompson & Yakura, 2001).

Multidisciplinary research emphases in aging with SCI span physical, psychological and social aspects of aging. Many of these studies focus on quality of life and/or life satisfaction, while others examine employment status and/or access issues. Table 1 lists common themes found in a review of key studies in this body of literature.

Table 1

*Multidisciplinary Research Emphases in Aging with SCI*

- 
- Quality of life
  - Life satisfaction
  - Access to care
  - Functional impairment
  - Specific secondary conditions & related treatments
    - Urinary tract/renal complications
    - Pulmonary complications
    - Cardiovascular risk factors
    - Musculoskeletal problems
    - Pain, fatigue
- 

One recent report from a multidisciplinary study detailed a number of self-reported problems in individuals aging with any SCI (Krause, 2007). In a 15-year multisite longitudinal study, researchers conducted phone or face-to-face interviews every five years with 800 individuals living with SCI, 449 of whom participated through the full 15 years (Charlifue, 2007). The interviews yielded a list of self-reported problems encompassing a broad range of concerns (see Table 2), including the general category of “health problems”. These health problems (e.g. fatigue, urinary tract infections, weight changes, skin breakdown) reflect changes associated with the physical aspects of aging.



Table 2

*Self-Reported Problems in Aging with SCI*

---

Pain
Loneliness
Lack of control over your life
Difficulty making new friends
Lack of adequate income
Boredom
Lack of transportation
Dependency
Health problems
Depression
Family problems
Conflicts with attendants
Negative attitudes toward the disabled
Lack of accessibility
Alcohol or drug abuse
Stress

---

*Note:* Adapted from Krause, J.S. (2007). Self-reported problems after spinal cord injury: Implications for rehabilitation practice. *Topics in Spinal Cord Injury Rehabilitation*, 12(3), 35-44.

**Physical Aging with a SCI**

Physical, or biological aging is generally associated with a gradual decline in physical function (Kemp et al., 2004; Liem et al., 2004; Menter, 1992; Thompson & Yakura, 2001).

Common scientific and lay use of the term *biological aging* implies “the progressive

deterioration during the adult period of life that underlies an increasing vulnerability to challenges and a decreasing ability of the organism to survive” (Masoro, 2006, p.44). Physical aspects of aging can be expressed through a variety of changes in physical function. For example, a very common physical change associated with aging is presbyopia, a decrease in visual focusing ability that occurs in most adults by their mid-forties (Atchison, 2008; Charman, 2008; Holden et al., 2008). In women, the physical changes associated with the menopause transition serve as another common marker of aging, and are generally accepted as a part of the “normal” aging process for women between 40 and 60 years of age (Halliday & Boughton, 2009). These changes in physical function occur regardless of SCI status (Kalpakijian et al., 2010).

However, aging with a SCI appears to alter the aging process in certain body systems (Hitzig et al., 2008; Kemp et al., 2004; Menter, 1992; Thompson & Yakura, 2001). Aging-related declines in physical function are co-mingled with impairments resulting from the SCI. The pre-existing impairments may accelerate the onset of aging-related changes, creating a “premature aging” in this population (Hitzig et al., 2008; McColl et al., 2002; Menter, 1992; Thompson & Yakura, 2001). Table 3 provides a listing of the changes in physical function that appear to be increased or accelerated in many individuals aging with an SCI.

Table 3

*Changes in Physical Function Reported in Persons Aging with SCI*

Changes in Physical Function	Citation
Pain	Charlifue, 2007 Charlifue et al., 2004 Coll, 2007 Kennedy et al., 2006 Krause, 2007 McColl et al., 2002 McColl et al., 2004
Pressure ulcers	Charlifue et al., 2004 Krause, 2000 McColl et al., 2004 Whiteneck et al., 1992
Changes in bladder function	Krause, 2000 Ku et al., 2005 McColl et al., 2002 Price et al., 2004
Loss of muscle strength/ changed mobility	Charlifue, 2007 Krause, 2000 Krause & Coker, 2006
Fatigue	Fawkes-Kirby et al., 2007 McColl et al., 2004 Price et al., 2004

Bowel dysfunction	Charlifue, 2007 Coll, 2007 Krause, 2000 McColl et al., 2002 Price et al., 2004
Cardiac disease	Charlifue et al., 1999 Bauman et al., 1998 Szlachic et al., 2007
Pulmonary disease	Linn et al., 2000
Altered glucose tolerance	Bauman et al., 1999 Charlifue et al., 1999 McColl et al., 2004

These studies reflect changes in physical function experienced by the traumatic SCI population, including both complete and incomplete injuries. For the purposes of this study, the next phase of the literature review is to look more specifically at these changes in individuals with incomplete injuries.

### **Physical Aging with Incomplete SCI: Changes in Physical Function**

An integrative review of the literature was undertaken to identify empirical studies of changes in physical function experienced by individuals aging with incomplete SCI. Many studies examining the complex phenomenon of the biological aspects of aging with a SCI included subjects with incomplete injuries in their samples, and some reported results by subgroups. However, no scientific inquiry into the occurrence of physical changes specific to individuals aging with incomplete lesions has been published to date. Thus, the empirical

literature on aging with a SCI was mined in order to identify changes in physical function associated with aging with a traumatic incomplete SCI.

**Process of the integrative review.** Garrard's (2007) Matrix Method provided the design for this integrative review. An initial search was undertaken utilizing the PubMed and CINAHL databases. The search was limited to research published in English. No publication date limitations were enforced in order to glean a thorough historic perspective on the research in this area. The keywords utilized were *incomplete spinal cord injury* AND (*aging* OR *long term* OR *chronic*). The yield was 214 articles from PubMed and 156 from CINAHL, for a total of 370 references. A review of titles and/or abstracts eliminated all but 42 of these articles. Subsequent careful reading of these 42 decreased the number of articles to five. Extensive ancestry searching utilizing the reference lists of these five articles, as well as sources cited in a number of non-research publications, provided four additional articles. Finally, hand searching of selected journals (*Archives of Physical Medicine and Rehabilitation*, *Spinal Cord*, and *Topics in Spinal Cord Injury Rehabilitation*) provided two additional articles. A total of 11 articles was included in the final analysis.

Articles were retained if they were empirical studies of *physical changes* experienced by individuals aging with SCI. Another criterion for inclusion focused on duration of injury (DOI). Establishing a significant duration of injury is necessary in order to differentiate the experience of aging *with* an incomplete SCI from a distinct group of elderly individuals with *new* spinal cord injuries (DeVivo, Krause & Lammertse, et al,1999; McGlinchey-Berroth, Morrow, Ahlquist, Sarkarati and Minaker, 1995; Thompson & Yakura, 2001). Based upon an unpublished previous review of the literature by the researcher regarding aging with a SCI, a 20-year duration of injury was initially identified as an appropriate parameter for defining aging, particularly since a

number of longitudinal studies have passed this mark, with some published studies reaching thirty to forty years post-injury (Charlifue, Lammertse & Adkins, 2004; DeVivo et al., 1999; Kemp et al., 2004; McColl et al., 1999). However, strict adherence to this parameter proved to be too limiting, and the criterion was modified to retain articles if the DOI range included 20 years and reported an average duration greater than 10 years for the study sample.

Articles were included if the sample was comprised of individuals with traumatic injuries. In recent years, some researchers have begun to include non-traumatic changes to the spinal cord in their study populations. This can contribute to a lack of specificity in determining the DOI, particularly if the SCI etiologies are degenerative.

Articles were retained if they included a comparison of individuals with incomplete versus complete SCI. Most studies that included both categories of subjects (complete and incomplete SCI), but did not examine the two groups to determine similarities and/or differences, were excluded. However, two studies comprised primarily of persons with incomplete injuries were retained. Studies were also excluded if they examined individuals who sustained pediatric injuries. SCI's that occur prior to physical maturity often interfere with normal growth and development. This in turn will alter the experience of aging, creating another unique population (Anderson, Vogel, Willis & Betz, 2006; Kemp et al., 2004; Webster & Kennedy, 2007).

**Description of the integrative review sample.** After determining relevance, each article selected for inclusion was abstracted and rated for rigor (Garrard, 2007), with each of these 11 studies receiving a "high rigor" mark. A matrix was then developed to display authors, year of publication, country of origin, sample characteristics, purpose, research design, and results (See Appendix B). The 11 studies included in the integrative review were published between 1992 and 2007. All 11 studies were descriptive in nature, including five retrospective, four cross-

sectional, and two longitudinal studies. The great majority of these studies were authored by multidisciplinary teams (physicians, psychologists, social workers, physical therapists), with the exception of two studies that appear to be written by a team of urologists. None of the authors was identified as a nurse. The studies were conducted in the United States (4), the United Kingdom (4), South Korea (2) and Canada (1). Sample sizes ranged from 43 to 834, with a total of 2,789 subjects, 973 of whom had incomplete SCI. Duration of injury (DOI) ranged from 0.8 to 53 years across the studies, although two studies simply identified their sample as having a DOI greater than 20 years.

**Findings from the integrative review.** According to this body of literature, individuals aging with traumatic incomplete spinal cord injuries experience physical changes in a number of different body systems. Some of these changes are the same changes observed in persons aging with traumatic complete SCI. Some changes are seen more frequently in individuals aging with incomplete injuries, while others are less commonly experienced with incomplete injuries (as opposed to those aging with complete SCI's). Table 4 displays a summary of these changes, which are addressed in more detail below.

Table 4

*Physical Changes in Persons Aging with an Incomplete v. Complete Traumatic SCI*

<b>Changes occurring Equally in Persons with Complete and Incomplete SCI</b>
<ul style="list-style-type: none"><li>• EKG changes (in persons with abnormal lipid profiles)</li><li>• Constipation</li><li>• Increased bowel accidents</li><li>• Decreased renal function</li><li>• Pyelonephritis</li><li>• Renal stones</li><li>• Weakness</li></ul>
<b>Changes with a Higher Incidence in Persons with Incomplete SCI</b>
<ul style="list-style-type: none"><li>• Fatigue</li><li>• Pain</li><li>• Epididymo-orchitis</li><li>• Neoplasms</li><li>• Cardiac deaths</li></ul>
<b>Changes with a Lower Incidence in Persons with Incomplete SCI</b>
<ul style="list-style-type: none"><li>• UTI</li><li>• Lowered bone mass density (osteoporosis)</li><li>• Pulmonary functional loss (in tetraplegia)</li></ul>



*Aging changes common to both complete and incomplete SCI.* A number of physical changes were reported to occur proportionally in persons aging with complete compared to incomplete SCIs. Szlachcic, Carrother, Adkins, and Wagers (2007) explored the significance of abnormal electrocardiogram findings in persons aging with SCI as well as abnormal lipid profiles. A sample of records of 43 individuals with chronic spinal cord injury (mean DOI = 16.6 years) and concurrent abnormal lipid profiles was examined for ECG changes via a retrospective chart review. The study demonstrated that an increased duration of injury (DOI) was the sole parameter associated with electrocardiogram (ECG) abnormalities ( $p=0.0024$ ), indicating an increased risk for cardiovascular disease as DOI increases. The sample included 12 individuals (27.9%) with incomplete SCI. No significant differences in ECG abnormalities were found based upon injury completeness (Szlachcic et al., 2007).

Menter et al. (1997) undertook a descriptive study of 221 individuals aging with SCI. The sample included 47 individuals with incomplete SCI, and all participants had a DOI greater than 20 years. The purpose of this study was to examine the incidence of bowel complications associated with various bowel management techniques, as well as to examine the effects of both aging and DOI on bowel complications. The researchers found a significant relationship between DOI and constipation, with the odds of being diagnosed with constipation increasing 2.31 times for every decade post-SCI, regardless of completeness of injury ( $p=0.005$ ). Increased incidence of fecal incontinence was also the same for complete and incomplete SCI. The diagnosis of hemorrhoids increased with increasing age, but was not significantly associated with DOI.

Drake et al. (2005) evaluated the urological effects of aging in chronic spinal cord injury. Their sample of 196 individuals included 37 with incomplete SCI. The mean DOI was 33 years.

A significant relationship was found between increased DOI and declining renal function across neurologic categories ( $p=0.001$ ).

A study by Ku et al. (2005) examined the occurrence of upper urinary tract complications in a sample of 179 individuals with long-term SCI (mean DOI = 29.3 years), including 138 (77%) with incomplete injuries. The specific focus of this study was to compare the risks of upper urinary tract complications in relation to bladder management methods. The high incidence of urological complications in patients with SCI was not established in this study, but was assumed based upon previous research. Ku et al. (2005) specifically examined pyelonephritis, renal calculi, and upper urinary tract deterioration in people aging with SCI, and reported no significant differences in complete versus incomplete injuries.

Another physical change reported to occur proportionally in those aging with complete versus incomplete SCI is weakness. In an early study on aging with SCI, Gerhart, Bergstrom, Charlifue, Menter, and Whiteneck (1993) examined and interviewed 279 individuals aging with a SCI for at least 20 years. The results showed increased self-reports of functional decline over time, characterized by weakness and fatigue, that were not significantly different based upon injury completeness.

***Aging Changes with Higher Incidence in Incomplete SCI.*** Fawkes-Kirby et al. (2007) specifically investigated the clinical correlates of fatigue in chronic SCI. A retrospective review of the medical records of 76 individuals with SCI revealed that an incomplete injury was the lone significant correlate with increased fatigue ( $p=0.02$ ) in this sample. Pain alone was not statistically significant, but together, fatigue and pain accounted for 18 percent of the variance in fatigue scores.

Whiteneck et al. (1992) authored the earliest empirical study addressing physical changes in persons aging with an incomplete SCI (total n = 834, incomplete n = 322). The primary focus of their research was to identify mortality, morbidity, and psychosocial outcomes in injured persons with a DOI greater than 20 years. Most of the reported data in this study did not include a comparison of incomplete and complete injuries. The only comparisons they presented showed a higher percentage of neoplasms and cardiac deaths in individuals aging with incomplete SCI.

One genito-urinary change that was reported to occur more in the population with traumatic incomplete SCI was epididymo-orchitis. Ku, Jung, Lee, Park, and Shim (2006) studied an aging population (mean DOI = 16.9) of 140 spinal cord injured men, 75.7 % (n = 106) of whom had incomplete injuries. The researchers propose that the increased occurrence of epididymo-orchitis is related to a specific urinary management protocol commonly used by men with incomplete SCI: clean intermittent catheterization.

***Aging Changes with Lower Incidence in Incomplete SCI.*** Drake et al. (2005) conducted a study evaluating the urological effects of aging with a SCI. Their sample included 196 individuals with SCI, 37 of whom were living with incomplete SCI. The DOI for the complete sample ranged from 26 to 51 years (mean = 33 years). They reported that increased age and DOI were significantly associated with declining renal function (measured by serum urea and creatinine), regardless of completeness of injury ( $p = 0.001$ ). However, a lower incidence of urinary tract infections was shown in those aging with incomplete injuries ( $p < 0.01$ ).

Garland, Adkins, Rah, and Stewart (2001) found lowered bone mass density with increased DOI across their study sample ( $r = 0.25$ ;  $p < 0.001$ ). However, subjects with incomplete injuries had significantly less osteoporotic changes than their counterparts with

complete injuries, particularly as regards osteoporotic changes in the knee ( $p < 0.0001$ ). Finally, two studies (Linn et al., 2000; Linn et al., 2001) found that pulmonary function decreases with increasing DOI, particularly with tetraplegia, but that this change is mitigated by incomplete tetraplegic lesions ( $p < 0.01$ ).

**Summary of integrative review findings.** There is a substantial and growing body of empirical research literature describing physical changes experienced by individuals aging with traumatic SCI. A small portion of that research includes an analysis of the sub-population of persons aging with a traumatic incomplete SCI. Eleven studies yielded a list of physical changes seen in these individuals (see Table 3 for the summary of reported physical changes). Few of these changes were confirmed in more than one study.

Generalizability of these findings is greatly limited by the small sample size contributing to each reported change. However, this list provides a starting point for building a body of knowledge about the physical changes experienced by individuals aging with an incomplete SCI.

### **A Qualitative Study in the Literature**

In addition to the quantitative research identified, one qualitative study was found that provides some background for the proposed study. Pentland et al. (2002) utilized a combination of three focus groups ( $n=10$ ) and individual interviews ( $n=19$ ) to identify age-related changes experienced by women with SCI. The 29 participants' ages ranged from 35 to 70, with a mean age of 50 years. Their injury DOI's ranged from 3 to 38 years, with a mean of 12 years. No specific information was reported about injury completeness, however, seven participants identified walking (including with a cane) as their means of mobility, which would indicate that at least these women had incomplete SCI. Various themes emerged regarding physical changes. Gynecological and sexual issues, including concerns relative to menopause, were the most

frequently reported changes, followed by bowel and bladder changes, which were often linked to menstrual cycle changes. Other physical changes included musculoskeletal pain and loss, fatigue, increased skin vulnerability, and weight gain (Pentland et al., 2002). The report indicated that physical changes experienced by women with lower and/or incomplete SCI include decreased energy and increased pain. However, no other physical changes were specified to the sub-population of women with incomplete injuries (Pentland et al., 2002). No qualitative studies were found that described the experience of men aging with an incomplete SCI.

### **Challenges in the Literature Review**

A number of challenges arise in the process of identifying relevant research and integrating findings to establish a knowledge base. Many studies examining the complex phenomenon of physical aging with a SCI included subjects with incomplete injuries in their samples, but did not group these subjects for analysis. Other studies did statistically separate subjects with complete and incomplete injuries, but they clustered the data in incomparable, nonstandard groupings. For example, some studies combined all data describing all persons with paraplegia and incomplete tetraplegia, and compared those data to descriptions of persons with complete tetraplegia. Many studies referenced “chronic SCI” but included subjects who have injury durations as low as 2 years in their “long-term injury” group. Finally, there was a lack of standardization of definitions and interpretations of the terms “complete” and “incomplete” evident in the literature.

### **Summary of the Literature Review**

Perhaps the most remarkable finding gleaned from this review of the literature is the paucity of research that specifically examines the changes in physical function experienced by

individuals aging with a traumatic incomplete SCI. Based upon the fact that approximately 60% of the spinal cord injured population is living with an incomplete SCI (NSCISC, 2012), and that the proportion of incomplete injuries is rising (DeVivo, 2012), there is clearly a need for more research in this area.

Additionally, there is a paucity of qualitative research literature addressing the phenomenon of aging with any SCI from the perspective of the injured individual. To date, there is no published qualitative research specifically about the changes in physical function experienced by individuals aging with a traumatic incomplete SCI. This study is necessary to begin to fill this gap in the literature by describing the changes in physical function experienced by individuals aging through middle age with a traumatic incomplete spinal cord injury, from their own perspectives.

### **Significance of the Study to Nursing**

A thorough description of the changes in physical function experienced by people aging with a traumatic incomplete SCI can positively impact the nursing care provided to these individuals. For example, evidence-based anticipatory guidance offered by nurses in the acute rehabilitation setting may promote behaviors that could facilitate patients' future transition through middle age. Community-based primary care providers with increased knowledge about the physical changes common in individuals aging with an incomplete SCI could be better equipped to facilitate the transition through health-promoting and preventative strategies, as well as providing appropriate care when changes do occur. Additionally, this knowledge base may provide a foundation for nurses to reach beyond the immediate needs of the individual to impact health policy which would benefit persons aging with incomplete SCI. Health policies that facilitate access to care for those aging with a disability are often needed (Trupin & Rice, 1997),

and SCI nurses can play a key role in “addressing the needs of the individual [and] of the social network” (Starkweather, 2008). Understanding more about the physical changes experienced by individuals transitioning through middle age with a traumatic incomplete SCI can inform nurses in their roles as educators, caregivers and health promoters.

## Chapter 2

### Theoretical Framework

This chapter describes the theoretical framework supporting this study's design. The components of the theory are defined and applied to frame the current study. This is followed by a brief overview of how this theory has been used in other research.

#### **Theoretical Underpinnings**

The theoretical framework undergirding this study is the transitions theory conceptualized by Meleis, Sawyer, Im, Schumacher, and Messias (2000). This middle-range theory explicates the experience of moving from one status or condition to another. Transitions are complex, multidimensional processes which can include health and illness experiences as well as lifespan transitions such as aging (Meleis et al., 2000; Meleis, 2007). Several concepts within this theory are congruent with the focus of this study. Transition theory provided an appropriate framework for exploring the experience of individuals who are aging through middle age with a traumatic incomplete SCI.

The transition theory model (Figure 1) includes four primary components: the nature of transitions, facilitating and inhibiting conditions, patterns of response, and nursing therapeutics (Meleis et al., 2000). This study primarily focused on gaining a rich description of the nature of the transition, including types, patterns and properties. In addition, this study explored personal transition conditions, particularly in regard to preparation and knowledge.

#### **Types and Patterns of Transition**

Meleis et al. (2000) propose four different types of transitions that individuals and families encounter: developmental, situational, health and illness, and organizational.



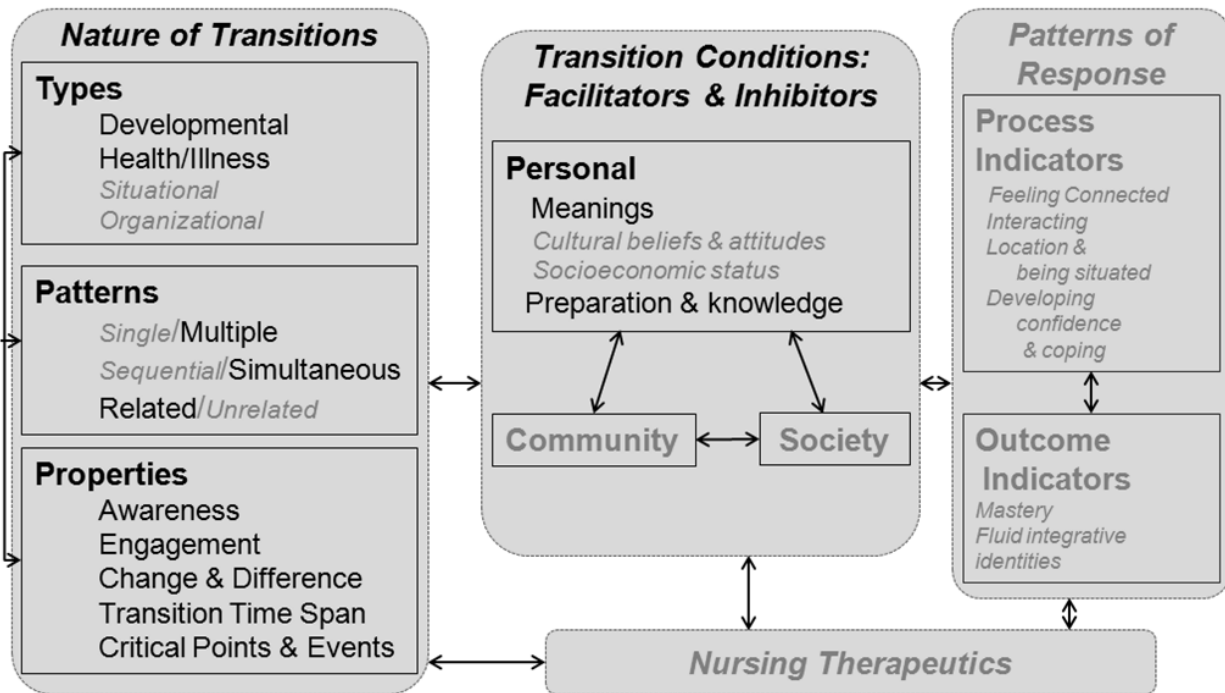


Figure 1. Transitions: A middle-range theory. Adapted from: Meleis, A.I., Sawyer, L.M., Im, E.O., Schumacher, K. and Messias, D.K.(2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science*, 23, 12-28. Bold concepts were explored in this study.

Transition experiences rarely occur in isolation from other types of transition. Examination of the patterns of transitions indicates that transition experiences are complex, and periods of time are often associated with multiple transitions (Meleis et al., 2000). These multiple transitions may occur sequentially or simultaneously. It is important to consider whether multiple transitions are related or unrelated to each other (Meleis et al., 2000). Individuals aging through middle age with a traumatic incomplete SCI appear to be facing two simultaneous and related transition types. One is the developmental transition of aging, specifically, the physical changes that accompany the aging experience. The other is the health and illness transition associated with the physical changes related to chronic SCI.

**Aging: A developmental transition.** The experience of aging can be conceptualized as a developmental transition (Meleis, 2007). From a biological perspective, aging has been defined as “a process of intrinsic, progressive and generalized physical deterioration” (Austad, 2001, p.3). However, specifying an actual time frame for this transition is elusive. Physical aging is said to begin at the age of reproductive maturity (Austad, 2001) or in the early twenties (Adkins, 2004; Weinel, 2005), when biologic capacity reaches its peak (Capoor & Stein, 2005). However, there is clearly a lack of specific and accurate biological markers to define aging (Austad, 2001; NIA, 2008; Timiras, 2007). In fact, the paucity of biological markers to define aging has been cited as a deterrent to research into the experience of aging (Timiras, 2007).

Aging, in its simplest form, is the process of growing older. However, an understanding of the aging process is not at all simple. Aging is a complex, multidimensional transition (Aldwin & Gilmer, 2004) with a wide variety of genetic and environmental factors that determine an individual’s aging experience (Austad, 2001; NIA, 2008; Timiras, 2007). This complex experience can actually be described as a series of transitions. For example, one developmental transition that has been identified is the period of time when an individual transitions “from adulthood to mature adulthood” (Meleis, 2007, p.470). The context of this study was the developmental transition of aging through the middle age years, defined as ages 40 through 60. One major factor that can further complicate the aging transition through middle age is the superimposition of disease or disability (Aldwin & Gilmer, 2004; Timiras, 2007).

**Incomplete SCI: A health and illness transition.** Successful treatment of acute traumatic SCI and management of complications has created a new population: people living with chronic SCI. Life expectancy for all Americans has increased approximately 35% since 1940, but a much more profound increase, almost 2000%, has been calculated for individuals

with an SCI (Adkins, 2001). This means that individuals are living with SCI for a much longer time, or an increased DOI. As DOI increases, it appears that numerous changes in physical function occur (Adkins, 2004; Hitzig et al., 2010; Krause, 2000; McColl et al., 2002; Savic et al., 2010; Whiteneck et al., 1992).

### **Aging with an incomplete SCI: Multiple simultaneous and related transitions.**

Aging with a traumatic incomplete SCI involves overlapping transition types. Recent estimates project that 40% of spinal cord injured individuals are over the age of 45, and at least 25% of these people have lived with SCI for at least 20 years (Cristian, 2004; Weinel, 2005). Some changes in physical function are associated directly with aging. Other changes are related to chronic SCI. Some changes may be due to the interplay between these two transitions. In fact, aging with any SCI has been proposed as a model for premature, or accelerated aging (Adkins, 2004; Bauman & Spungeon, 1994; Hitzig et al., 2010). Clearly, the experience of aging with an incomplete SCI must be explored as multiple, simultaneous and related transitions. For these reasons, the middle-range nursing theory of transitions provides appropriate theoretical underpinnings for this study.

### **Properties of Transition**

Transition experiences are highly complex and unique. However, there are five interrelated components, or properties, that can be identified in all transitions. These include awareness, engagement, change and difference, time span, and critical points and events (Meleis et al., 2000). These properties framed the data collection about participants' experiences of changes in physical function as they transition through middle age.

**Awareness.** Transition is marked by an individual's recognition and perception of the transition, which Meleis et al. (2000) label as awareness. An individual's level of awareness will

greatly impact the transition experience. Awareness is often gauged by comparing what the individual perceives about his or her transition with an established set of parameters experienced by other individuals undergoing a similar transition (Meleis et al., 2000). Because so little is known about the physical changes that occur during the experience of aging with an incomplete SCI, a comparison to an established data set was not possible. Instead, this study has provided an initial description of physical changes that can be further developed in future research. Exploration of individuals' awareness of changes in physical function as they transition through middle age was paramount in this study, as the purpose was to describe this transition experience from their point of view.

**Engagement.** Based upon a foundation of awareness, the individual may become involved, or engaged, in the transition. Engagement is demonstrated by active participation in preparing for and facing challenges through seeking information and altering activities (Meleis et al., 2000). Identifying and utilizing role models who have undergone a similar transition is another hallmark of engagement. In this study, engagement was explored through describing the individual's avenues of information-seeking. Also, strategies that indicate preparation for physical change were explored.

**Change and difference.** Two closely related properties of transition are change and difference. Change may be associated with disruptions in routines, or with a specific "critical or disequilibrating event" (Meleis et al., 2000, p.19). According to Meleis and colleagues, aspects of change that should be explored include perceived severity or importance and temporality. All transition experiences involve change, but the concepts of transition and change are not synonymous. For example, a specific event such as a fall or an infection may precipitate an abrupt change in focus for an individual aging with an incomplete SCI. This change may initiate

a longer-term process of transition, which might involve coming to terms with new limitations and mastering new routines.

Difference is another essential property of transitions. Difference is “exemplified by unmet or divergent expectations” (Meleis et al., 2000, p.20). As individuals with incomplete SCI’s age, it may be that the reality of their physical and functional abilities is different than what they anticipated. For example, a person who regained independent ambulatory abilities during acute rehabilitation in early adulthood may not have anticipated the need for ambulatory aids as he ages through his middle-aged years. However, the disparity between expectations and reality is not necessarily negative (Meleis et al., 2000). A person aging with an incomplete SCI may have anticipated particular deterioration in physical function, and that change may not have occurred.

**Time span.** Transitions are “characterized by flow and movement over time” (Meleis et al, 2000, p. 20). Some transitions have a clearly defined beginning and end, but many transitions are not amenable to clear boundaries (Meleis et al., 2000; Skarsater & Willman, 2006). The developmental transition of aging through middle age defies specific standardized temporal boundaries, and this holds true for those aging with incomplete SCI as well. This study will describe the span of time participants associate with changes in physical function during the transition through middle age.

**Critical points and events.** While transitions occur over a span of time, most transition experiences include a number of critical points. These critical points often involve an event where an individual’s awareness of changes and differences is increased, or where the individual becomes more engaged in the transition (Meleis et al., 2000). For an individual aging with an incomplete SCI, this may take many forms. The literature indicates that these critical points may

include, for example, the recognition of a new limitation in ambulation or mobility (Charlifue, 2007; Krause & Coker, 2006), the discovery of a pressure ulcer (Charlifue et al., 2004; Krause, 2000; McColl et al., 2004), or the diagnosis of a new secondary condition (Bauman et al., 1998; Charlifue, Weitzencamp, & Whiteneck, 1999; Cristian, 2004; Hitzig et al., 2008; Linn et al., 2000; McColl, Charlifue, Glass, Lawson, & Savic, 2004; Szlachic et al., 2007).

### **Transition Conditions**

In addition to the interrelated properties of a transition experience, the theory also identifies several facilitators and inhibitors, or transition conditions (Meleis et al., 2000). These include personal, community, and societal conditions that can promote or inhibit a healthy transition. The personal transition conditions include meanings, cultural beliefs and attitudes, socioeconomic status, and preparation and knowledge. Community resources which impact transitions may include family and peer support, information from healthcare providers, and online or written materials (Meleis, 2000). As the analysis progresses, the data may reveal personal and community transition conditions that impact the experience of aging through the middle age years with an incomplete SCI. Of particular interest in this study were the personal transition condition of preparation and knowledge, and the community conditions related to preparation and knowledge.

The lack of evidence regarding the experience of aging with an incomplete SCI is clear. This has arguably had a negative effect on the ability to prepare for a healthy transition (Skarsater & Willman, 2006). Inadequate teaching and anticipatory guidance from the acute rehabilitation period onward can limit health-promoting behaviors and reduce care-seeking. Individuals aging with any SCI report that a lack of expertise regarding long-term SCI within the general cadre of primary care providers persists (Charlifue, 2007; Donnelly, McColl, Charlifue,

Glass, O'Brien, & Savic, 2007; Pentland et al., 2002), identifying this as the greatest barrier to needs being met (Cox, Amsters & Pershouse, 2001). Certainly the dearth of research in aging with an incomplete SCI perpetuates this lack of knowledge, and subsequently compromises the quality of care that injured individuals receive (Weinel, 2005). Expanding the body of scientific knowledge in this area would equip health care providers as well as individuals aging with traumatic incomplete SCI's by providing a foundation for anticipatory guidance, facilitating this time of transition.

### **Use of Transitions Theory in Research**

The middle-range transitions theory has been cited as the theoretical foundation for many research studies, and has provided the basis for a number of situation-specific theories related to transitions (Hattar-Pollara, 2010; Meleis, 2010). Some developmental transitions that have been explored include becoming a first-time African American mother (Sawyer, 1999) and the experience of menopause for Korean immigrant women (Im & Meleis, 1999). Empirical examinations of a variety of situational transitions have supported the theory, including the transition of hospital discharge (Weiss et al., 2007) as well as long-term care placement of elders (Rossen & Knafl, 2007). Another study focused on the experience of relatives involved in their elderly family member's transition into a nursing home (Davies, 2005). That study supported Meleis' model, but suggested that the theory was somewhat limited in its emphasis on the significance of reciprocal relationships between individuals involved in the transition.

Transition theory has also been used to explore a number of different health and illness transitions. Some examples include Mexican American women with a new diagnosis of diabetes (McEwen, Baird, Pasvogel & Gallegos, 2007), women living with rheumatoid arthritis (Shaul, 1997), Swedish elders admitted to rehabilitation following hip fracture (Olsson, Nystrom,

Karlsson & Ekman, 2007), and the transition towards end of life experienced by cancer patients in palliative care (Larkin, Dierckx de Casterle & Schotsmans, 2007). Additionally, the transition theory has been used to examine organizational transitions such as the experience of adjusting from a unit-based nursing position to working in a flexible staffing model (Rich, 2010).

### **Summary of Theoretical Framework**

The theory proposed by Meleis and her colleagues continues to provide a framework for research into the experience of transitions and human responses to those transitions (Meleis, 2010). There is a wide variety of transition types, and their patterns are often complex, frequently involving multiple overlapping transitions (Meleis, 2010). The transitions theory proposed by Meleis et al. (2000) provided an appropriate framework for exploring the experience of individuals who are aging with an incomplete SCI. Both the developmental transition of aging and the health/illness transition related to effects of an incomplete SCI framed the study design. Based upon a review of research and non-research literature, the patterns of these multiple transitions were understood to be simultaneous and related. Elements of each transition property were explored: awareness, engagement, change and difference, time span, and critical points and events. The study also included some exploration of some personal transition conditions, particularly preparation and knowledge. In keeping with the qualitative descriptive study design, attention was also given to the meaning participants attributed to the transition (Sandelowski, 2000).



## Chapter 3

### Methods

This chapter describes the study's qualitative descriptive design, setting, and procedures for sampling, data collection, data management, data analysis, and reporting. Strategies for establishing trustworthiness and the protection of human subjects are also explained. Attention to each of these elements is essential in the process of accurately describing the participants' perceptions of the changes in physical function they experienced while transitioning through the middle-age years with a traumatic incomplete SCI.

#### **Design**

Grounded in a philosophy of natural inquiry, qualitative description (QD) seeks to provide a rich, lucid description of an experience from the participants' points of view (Sandelowski, 2000; Sandelowski, 2010). QD is an ideal method for gaining understanding of human experiences and describing complex processes (Sullivan-Bolyai, Bova, & Harper, 2005). QD has also been identified as an appropriate method for use with vulnerable populations (Sullivan-Bolyai et al., 2005). Individuals with disabilities, including those with a traumatic incomplete SCI, have been identified as the largest minority group in the U.S. (U.S. Department of Health & Human Services, 2005). The complexities of aging with SCI adds to the physical, social and economic vulnerability of this population (Charlifue, 2007; Lammertse, 2001).

A number of different qualitative methods could be considered to explore the experience of aging with an incomplete SCI. The nature of aging as a process may suggest that grounded theory (GT) would be an appropriate methodology as well. There are definitely many similarities between QD and GT. Artinian (1996) identifies QD as a prerequisite to GT. Sandelowski (2000, p.337) acknowledges the potential inter-relatedness of QD and GT, stating

that "qualitative descriptive studies may have grounded theory overtones." QD, with "hues, tones and textures" of GT (Sandelowki, 2000, p.337) is the methodology of choice for seeking out the latent variables or mundane details that underlie the experience of aging with an incomplete SCI. The themes identified in the participants' descriptions of their changes in physical function in this QD study could be a first step toward the development of a grounded theory explaining the changes in physical function experienced by individuals transitioning through middle age with a traumatic incomplete SCI.

### **Setting**

Participants for this study were sought primarily through contacts in New England, but participants could live anywhere in the world; therefore this study setting would be described as at-large. Many individuals who experienced a traumatic incomplete SCI at least 15 years ago have long since been discharged from rehabilitation settings. They are not necessarily part of the same groups, and do not necessarily receive care in the same place. In order to enter into the field to make initial contact with potential participants, the researcher needed to find a means of communicating with this community-based population. Many individuals living with a long-term SCI subscribe to an email contact list overseen by staff at the New England Regional Spinal Cord Injury Center (NERSCIC) at Boston Medical Center. Southern New England is also the home of a support group for persons living with SCI called the Greater Boston Chapter (GBC) of the Spinal Cord Injury Association, and this organization also maintains an email contact list. The email contact lists from both of these groups facilitated contact with most of the study participants, from New England, across the US, and overseas.

Each participant who resided within a two hour driving distance of the researcher was given the option of participating in either a face-to-face interview or email interview. An email

interview format was utilized for all other participants. Details about the various recruitment and sampling strategies are discussed below.

### **Recruitment**

Multiple strategies for identifying and recruiting participants were proposed as part of the study design, and several of these strategies were utilized. Of these, some proved effective in reaching participants, while others did not yield any participants.

#### **Recruitment of Participants through the NERSCIC**

The NERSCIC is one of the 14 Model System centers that contribute to the database managed by the National Spinal Cord Injury Statistical Center (NSCISC). The NSCISC is funded through the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services. One of the stated purposes of the NSCISC is “to facilitate other research such as the identification of potential persons for enrollment in appropriate SCI ... research projects” (NSCISC, n.d.). The NERSCIC has approximately 900 active patients (personal communication, Steve Williams, M.D., NERSCIC Medical Director). Demographic characteristics and injury specifications from the national SCI database (Cristian, 2004; NSCISC, 2010; Weinel, 2005), suggested that approximately 110-190 of these individuals would meet the inclusion criteria for this study. In addition, the NERSCIC sponsors an ongoing series of education programs for SCI consumers and maintains their contact information in its email contact list. The longevity and purpose of the NERSCIC have established this clinic as a source of information in the New England region for individuals seeking to learn about SCI and those individuals who are interested in current research. Based upon this reputation, the NERSCIC email contact list provided a means of communication with a large number of individuals within the SCI population.

SCI scientists and caregivers at the NERSCIC presented, on behalf of the researcher, an invitation to any people who might be potential participants. The researcher did not have access to patient names or information, including the medical record of any potential participant. NERSCIC presented the invitation two ways. They sent the researcher's email invitation, describing the purpose of the study and eligibility requirements, to potential participants through the NERSCIC patient email contact list (Appendix C). Also, the NERSCIC staff distributed paper copies of the researcher's recruitment flier (Appendix D) for NERSCIC in the clinic. These emails and fliers included both a password protected telephone number and a password protected email address where potential participants could contact the researcher at their option.

Over the course of the study, 22 of the 36 individuals who inquired about potential participation responded as a result of the NERSCIC's email communication to its email contact list. Of these 22, nine were deemed eligible and chose to enroll in the study. No respondents indicated that they had received a paper flier in the clinic.

### **Recruitment of Participants through a Local SCI Support Group**

Participants were also sought through the GBC of the National Spinal Cord Injury Association (NSCIA). The GBC currently maintains an email list of 190 persons living with SCI (personal communication, Kevin Gibson, GBC Director). Based upon the same national SCI data (Cristian, 2004; NSCISC, 2010; Weinel, 2005), approximately 27- 44 individuals on that email list would meet the study inclusion criteria.

The GBC newsletter coordinator also placed an advertisement on behalf of the researcher in the GBC's electronic newsletter, which was posted on the GBC website. Organizational newsletters provide an effective means for communicating with a specific target audience (Kralich, Koch & Brady, 2000), and on-line special interest group sites have been identified as

an effective tool for participant recruitment (Cantrell & Lupinacci, 2007; Hamilton & Bowers, 2006; Holmes, 2009; Murray & Fisher, 2002). In addition, the GBC sent the researcher's email invitation (Appendix E) to the 190 individuals who make up the email contact list of the GBC. This list includes all GBC members, encompassing individuals with complete and incomplete injuries, as well as individuals with a wide range of injury duration. Email contact lists for consumer organizations provide a cost-free opportunity for recruitment communication, and have been effectively utilized to reach individuals with SCI living in the community (Kroll, Neri, & Ho, 2007). Communication through the GBC yielded 10 or 11 inquiries (one respondent was unclear about the source of the email advertisement he received, but timing would indicate that he received the GBC email), and five participants were enrolled as a result of this strategy.

### **Recruitment of Participants through other Healthcare Providers**

Local primary care providers (PCP's), urologists and physiatrists were contacted and asked to assist with recruitment by linking the researcher to any possible participants (Kroll et al., 2007). Practitioners in these three medical specialties were sought out because of their potential interaction with individuals aging with incomplete SCI. As the longevity of the spinal cord injured population has increased, the number of PCP's caring for individual's aging with incomplete SCI has expanded (Capoor & Stein, 2005; Donnelly et al., 2007; Harrington, Hirsch, Hammond, Norton & Bockenek, 2009; Kemp et al., 2004). Urologists were contacted based upon a review of the literature, which indicates that neurogenic bladder is one of the most common persistent problems experienced by individuals with SCI, including those with incomplete injuries (Drake et al., 2005; Ku et al., 2006). Local physiatrists were also approached. Physiatrists specialize in Physical Medicine and Rehabilitation, and thus may provide care to individuals with incomplete SCI, particularly if they have muscular impairment.

Preliminary phone calls were made to selected PCP, urology and physiatry practices in Massachusetts and Rhode Island to ascertain if there were potential participants in their practice, without request for any identifying data. Provider practices were selected based upon referrals from individuals active in the SCI community. If the preliminary phone call revealed one or more potential participants, and the physician and practice agreed, the researcher delivered copies of a letter describing the purpose of the study and eligibility requirements to these healthcare providers or their office staff for them to distribute to potential participants (Appendix F). Again, the researcher did not obtain any identifying information about potential recruits to the study until and unless recruits voluntarily contacted the researcher in response to receipt of a letter. This strategy, though promising, was not effective. Throughout the recruitment phase, one physiatry practice and one PCP each agreed to forward the letter to a qualified participant. However, no inquiries resulted from this strategy.

Additionally, a professional nursing colleague of the researcher forwarded the NESIC email describing the purpose of the study and eligibility requirements to a potential participant. This individual qualified for the study and enrolled.

### **Recruitment of Participants through Snowball Sampling**

Additionally, snowball sampling was used, meaning new participants were referred by enrolled participants (Faugier & Sargent, 1997; Morse & Richards, 2002). The researcher asked each participant to forward an email invitation to other potential participants. Providing the researcher's password protected contact information allowed these potential participants to respond if they were interested. Two individuals contacted the researcher as a result of snowball communication, and both of these individuals participated in the study.

### **Other Proposed Recruitment Strategies**

Several other recruitment strategies were planned, but not utilized. One planned strategy was to place a study flier on the community bulletin board in the SCI Outpatient Clinic at a local Veterans Administration Hospital. This clinic provides care for over 500 patients, the majority of whom sustained traumatic incomplete SCI. Although the clinic staff verbally agreed during the planning stages to allow the posting, they subsequently had to withdraw the offer to assist in recruitment of an external study, so this strategy was not feasible.

Data saturation was reached without needing to utilize two other planned strategies. Another proposed recruitment strategy was to place a request on national SCI association websites. Many of these sites include research bulletin boards which allow recruitment announcements to be posted free of charge (Cantrell & Lupinacci, 2007; Hamilton & Bowers, 2006). Another potential recruitment strategy was mailings (either through email or traditional mail) to individuals aging with incomplete SCI who are followed for their medical care at another SCI model center elsewhere in the US. However, working with another center at a distance from the researcher proved to be sufficiently complex as to render this strategy less feasible.

### **Summary of Recruitment Strategies**

Recruitment proved to be a challenging process. Communications via the NERSCIC and the GBC of the SCI Association were effective in reaching a total of 36 individuals who expressed an interest in study participation. Email contact was lost with two individuals after their first inquiry, and not enough information was shared to determine if these individuals would have been eligible to participate. Three others, who appeared to be eligible for inclusion in the study according to the initial screening questions, did not reply after the fact sheet was sent. According to the email consent process, this was interpreted as a voluntary decision to not

participate, and an email was sent stating that if they in fact wished to participate, they could re-contact the researcher. Another eligible individual agreed to participate, but then declined before starting the email interview, stating that he was too busy.

Seventeen people met the study criteria and chose to participate. These participants provided a rich description of the changes in physical function experienced in individuals transitioning through middle age with an incomplete SCI. Recruitment efforts ended after analysis of these 17 interviews when data saturation was reached. Data saturation occurs at the point where no new themes or information are observed in the data (Guest, Bunce & Johnson, 2006; Morse & Richards, 2002; Sandelowski, 2008).

### **Sampling**

Nonprobability sampling is generally associated with qualitative research, where smaller sample sizes are employed to investigate research questions that push beyond the boundaries of what is known (Kemper, Stringfield & Teddlie, 2003; Onwuegbuzie & Leech, 2005; Teddlie & Yu, 2007). This study used purposive and snowball sampling. Theoretical sampling, although planned, was not feasible.

Purposive sampling is the most common nonprobability sampling approach (Guest et al., 2006). A purposive sample is constructed by selecting participants who can provide detailed descriptions of the phenomenon of interest (Burns & Grove, 2005; Teddlie & Yu, 2007). In contrast to random samples, where the intent is to minimize bias, purposive sampling is deliberately biased (Sandelowski, 2008). This allows for “greater depth of information from a small number of carefully selected cases” (Teddlie & Yu, 2007, p.83).

As the sampling process was initiated, participants were purposively sought who could provide a description of the changes in physical function they have experienced or are



experiencing as they transition through middle age. As data were collected and analyzed, the original intent was to make sampling decisions which were influenced by emerging themes in the data. This process is referred to as theoretical sampling (Chen & Boore, 2009; Coyne, 1997; Glaser, 1992). Most commonly associated with grounded theory methods, theoretical sampling is a specific type of purposive sampling that deliberately seeks participants most apt to have knowledge of the experience being studied, allowing the researcher to more fully explore themes arising from the data (Chen & Boore, 2009; Coyne, 1997). However, as the challenging task of recruitment unfolded, theoretical sampling proved infeasible. Every qualified volunteer was included as a participant.

The study as proposed was intended to amass a targeted sample of 12 to 20 participants (Guest et al., 2006), and data saturation was reached at 17 participants. The original intent was to purposively seek participants who reflect the demographic characteristics of the SCI population. One anticipated challenge was to recruit women, as, according to the NSCISC (2010), a significant majority of individuals with SCI are male. Since the inception of the National SCI database, the proportion of males has remained fairly consistent at approximately 81 to 82 percent (NSCISC, 1994; NSCISC, 2010). Because a large majority of individuals with SCI are men, it was proposed that it might not be feasible to recruit enough women to fully describe their unique experiences within the context of this study. However, as recruitment unfolded, the numbers of men and women volunteering and enrolling stayed fairly equal.

### **Inclusion/Exclusion Criteria**

Participants were sought who could offer a description of the experience of aging through the middle age years with a traumatic incomplete SCI. Inclusion criteria regarding current age, DOI, and communication ability were considered.

### **Inclusion Based on Current Age**

The age requirement for inclusion in the study was within the range of 35 to 65 years. Participant age was ascertained by self-report. The age range of 40 to 60 includes individuals who are currently transitioning through middle age (Davis & Friedrich, 2010; Levinson, 1986). The inclusion of one individual younger than 40 (age 35) is consistent with the literature that proposes that aging with a SCI may be accelerating in comparison with the general population (Hitzig et al., 2008; McColl et al., 2002; Menter, 1992; Thompson & Yakura, 2001). Individuals up to the age of 65 were included (two 61-year-old participants and one 65 year-old). However, because the specific time frame of interest for this study is middle age (defined as age 40 through 60), issues of recall bias are potentially more likely to arise if individuals are further beyond the middle years. Thus, the inclusion age range did not go above age 65. Several individuals who inquired about participation were not enrolled because they were either under 35 (1 individual) or over 65 (2 individuals).

### **Inclusion Based on DOI**

Study participants included individuals with a traumatic incomplete SCI who are at least 15 years post-injury. This criterion was imposed to differentiate the experience of aging *with* an incomplete SCI from the experience of a distinct group of aged individuals with *new* spinal cord injuries (DeVivo et al, 1999; McGlinchey-Berroth et al., 1995; Thompson & Yakura, 2001). Injury specifications, including DOI and completeness were ascertained via participant self-report. Five individuals who inquired about participation were not included because their DOI was less than 15 years.

### **Inclusion Based on Incomplete Spinal Cord Injury Diagnosis**

While medical record verification would be ideal, costs associated with medical record reviews to confirm SCI diagnosis are prohibitive, and complete medical records were not necessarily available for some participants. A self-report of SCI diagnosis has been used in other studies (Hitzig et al., 2008; Kroll et al., 2007; Hammell, Miller, Forwell, Forman, & Jacobsen, 2009; Widerstrom-Noga, Felip-Cuervo, Broton, Duncan, & Yezierski, 1999), but “requires that a conservative approach be taken when interpreting findings” (Hitzig et al., 2008, p.553). As the purpose of this study was description with low-inference interpretation, medical record verification was not required for study participants. In addition, the majority of the study participants were recruited through an established SCI clinic, a physician practice, or through membership or participation in the Spinal Cord Injury Association. These specific recruitment strategies should have limited the risk of including participants without an actual incomplete SCI.

In an effort to further reduce the risk of including participants without an actual incomplete SCI, the researcher conducted a preliminary screening with each person who volunteered for the study. This screening included asking the potential participant to describe the level of his or her SCI as well as providing a general statement regarding the incompleteness of the SCI. The literature suggests that most individuals living with a SCI will be readily able to provide this information (Hammell et al., 2009; Hitzig et al., 2008; Kroll et al., 2007; Widerstrom-Noga et al., 1999). Each of the participants was able to articulate the level of injury, and describe the incomplete nature of the SCI. One individual who inquired about participation was not included because he described his SCI as complete. Another individual was not included because the nature of her injury was unclear from her description, and another

respondent was excluded because he stated that he identified with the SCI population, but had a different diagnosis.

### **Inclusion Based on Communication Ability**

Other inclusion criteria included the ability to understand and speak English, and the ability to respond meaningfully in a one to two hour interview, if the participant selected the face-to-face interview option. For those participants responding via email, inclusion necessitated the ability to communicate in English via email.

### **Exclusion Criteria**

Regardless of their current age, individuals who sustained pediatric injuries were excluded. SCI's that occur prior to physical maturity often interfere with normal growth and development. This in turn will alter the experience of aging, creating another unique population (Anderson, Vogel, Willis, & Betts, 2006; Kemp et al., 2004; Webster & Kennedy, 2007). Thus, individuals were excluded if their SCI occurred prior to age 16. Two individuals who inquired about participation were not included because their injuries occurred at birth or in childhood. In addition, individuals who sustained nontraumatic SCI were excluded. Nontraumatic SCI's, which include etiologies such as tumor and inflammation, are associated with different complications than SCI due to trauma (New et al., 2002; New & Sundararajan, 2008). Additionally, it is often impossible to identify a specific DOI with a nontraumatic etiology, also supporting the decision to limit the sample to individuals who sustained a traumatic SCI (McColl et al., 1999). Two individuals who inquired about participation were not included because their injuries were of a non-traumatic etiology.

Finally, individuals were excluded if they are unable to provide a description of their injury that would indicate that they indeed sustained a traumatic incomplete SCI. The vast

majority of individuals living with SCI are aware of their level and completeness of injury, and should be able to describe their SCI in those terms (Hammell et al., 2009; Hitzig et al., 2008; Kroll et al., 2007; Widerstrom-Noga et al., 1999).

### **Data Collection**

Self-reported data to determine if a potential participant met the criteria for inclusion was collected during an initial contact. This initial contact was by telephone for potential participants who contacted the researcher by telephone (n = 2). For the remainder of the inquiries, which came via email from the potential participants (n = 34), the initial contact from the researcher to determine study eligibility was done via email. Questions were embedded in an email rather than in an attached form. This strategy avoids issues such as software incompatibilities and fear about downloading a computer virus, and greatly increases response rates (Dommeyer & Moriarty, 2000; Meho, 2006).

A recruitment data log was created as an Excel file. Each inquiry from a potential participant was assigned a numeric code. The numeric code was the only means of identifying data from that individual throughout the study. The cross walk between the participants' names and their numeric codes was stored in a locked file in the researcher's office, separate from all other study data. Recruitment log data included the date of the inquiry, and whether or not the inquirer was enrolled in the study. This log also contained notations indicating the reasons for non-eligibility, as well as the potential participant's response to the question, "How did you hear about this study?" Again, a total of 36 individuals inquired about participation, and 17 of them qualified for the study.

Once it was determined that a potential participant met the criteria for inclusion in the study, the next step was to determine which interview method would be utilized. Local

participants (individuals residing within a two hour driving distance of the researcher) were given the option of participating in either a face-to-face interview or email interview. All other participants were invited to participate in an email interview.

Once the potential participant selected the interview method, the next step was to obtain informed consent. For the six individuals opting for a face-to-face interview, the consent form (Appendix G) was presented in writing to the potential participant prior to any data collection. These participants were also offered a copy of the consent form to keep. In this face-to-face context, interview data collection did not begin until the participant verbally expressed understanding of the study process, and signed the written consent form. Each participant was assured of his or her right to end the interview at any time.

For the 11 individuals participating via an email interview, a fact sheet (Appendix H) was emailed to the participant prior to sending any interview questions. This fact sheet was sent as an email attachment, and recipients were asked to confirm that they were able to open the attachment. Each participant was given as much time as he or she needed to read the fact sheet, and the researcher was available by email to answer any questions. The participant was then asked to confirm consent to participate via email. Continued email conversation indicated ongoing consent to participate. Again, the participant was assured of his or her right to discontinue the interview at any time.

### **Face-to-Face Interviews**

Face-to-face interviews took place at a site convenient for the participant, with consideration given to privacy and safety. Three of the interviews took place in the participants' homes, two at the participants' workplaces, and one in a restaurant. A safety plan was in place for in-home interviews (see Appendix I). Interviews were scheduled for up to two hours.

Demographic data, collected by self-report, included age, gender, race, education level, marital status, and state of residence. In addition, some information was collected from each participant indicating years since SCI, etiology of SCI, level of injury, and injury completeness. These data were used to support analysis, as well as to confirm eligibility data gleaned from the initial screening. This information was collected orally, recorded in a notebook by the researcher, and labeled only with the participant's numeric identification code. These de-identified data were entered into a password-protected Excel file for the analysis. The notebook of de-identified data was stored in a locked cabinet in the researcher's office, and the researcher will destroy the notebook five years after dissertation defense.

Qualitative data were collected through moderately structured individual interviews, consistent with the tenets of QD (Sandelowski, 2000; Sullivan-Bolyai, Bova, & Harper, 2005). Appendix J displays the initial Interview Guide, showing the questions that were used initially, along with sample probes for each question. As the data analysis proceeded, the probes were modified to allow for a rich description of emerging themes (Sullivan-Bolyai et al., 2005).

Each face-to-face interview was audio recorded using two personal digital recording devices (the second was for back-up in case the first failed). Each device was tested prior to each interview. The investigator created hand-written field notes immediately following each interview to record observations and reflections that were not captured in the audio recording (Creswell, 2003). These field notes informed the analysis and served as part of the study's audit trail.

### **Email Interviews**

As an alternative to face-to-face, audio-recorded interviews, which were available only to participants local (within two hours' drive) to the researcher's location, an email interview

format was employed. Local participants were given the choice of either face-to-face or email interviews, while participants outside of a two-hour drive radius were interviewed via email. Four local participants chose the email format (6 chose face-to-face), and the seven other email participants were from more distant geographic locations.

After obtaining consent, the researcher asked questions to glean demographic data and SCI specifics in an email. These questions sought the same data as the face-to-face interviews, including age, gender, race, education level, marital status, state of residence, etiology of SCI, level of injury, injury completeness, and DOI. This information confirmed the eligibility data provided by the participants during the initial screening, and was used to support analysis. Questions were embedded in the body of an email rather than in an attached form. The body of each email response was transferred into de-identified Word files marked with each participant's numeric code. Email addresses were not included in the Word files comprising the data for analysis. Participants' de-identified demographic data was entered into the study's password-protected Excel file for the analysis.

Moderately structured interviews were employed to collect qualitative data in email interviews, utilizing the same interview guide used for face-to-face interviews (Appendix J). Asynchronous email interviews are an iterative process, where a limited number of questions is first posed by the researcher, a response is sent by the participant, and then the researcher sends additional questions and probes (Beck, 2005; Im & Chee, 2003; McAuliffe, 2003; Meho, 2006). This interview format allows the obvious benefit of eliminating geographic barriers (Ahern, 2005; Beck, 2005; Cantrell & Lupinacci, 2007; East, Jackson, O'Brien & Peters, 2008; Hamilton & Bowers, 2006; Holmes, 2009; Im & Chee, 2003; Kralik et al., 2000; McAuliffe, 2003; Meho, 2006; McCoyd & Kerson, 2006; Murray & Fisher, 2002). Asynchronous interactions allow for



sustained discussion in spite of different time zones and schedules (Beck, 2005; Im & Chee, 2003). While the total time needed to actively participate in the interview may be approximately two hours, participant burden may be lessened because they are able to respond to questions when the time is best for them. Utilizing email interviews allowed for inclusion of a broader range of participants, which provided the opportunity for greater perspective on the topic of aging with an incomplete SCI.

Use of the email interview format limits the email participation to individuals who have internet access, which has been cited in the past as a potentially significant limitation (Hamilton & Bowers, 2006; Meho, 2006; Murray & Fisher, 2002). However, recent trends show an increase in internet usage in the United States. According to the Pew Research Center (2009), 77% of adults use the internet to send and receive email at least occasionally. Although internet usage is more common in younger adults, internet/email usage is reported in a majority of adults age 30-49 (83%) and age 50-64 (77%).

Another potential limitation of the email format is the added effort required by individuals with decreased use of their upper extremities to use a keyboard. One participant first opted for the email interview format, and then expressed the desire to interview face-to-face, stating that it would be easier to be “more expressive.” Another email participant described wear and tear injuries to her neck that were in part attributed to using a mouth stick to use the computer keyboard. While this woman did not indicate that her participation in the study was burdensome, her description of her wear and tear injuries highlighted the fact that long email interactions could be burdensome to individuals with neurologic deficits in their upper extremities, if those individuals do not have voice-activated software. Another email participant asked if she could talk to the researcher by phone, as she was too busy to continue with the email

interview. As telephone interviews were not included as a data collection method in the study proposal approved by the Institutional Review Board, , this request was not met.

### **Use of Two Data Collection Methods**

Utilizing both face-to-face and email interview formats brought the advantages of both formats to this study. For example, one frequently mentioned advantage of face-to-face interviews over email interviews is the ability to observe facial expressions and other body language (Beck, 2005; McAuliffe, 2003; Meho, 2006; Murray & Fisher, 2002). This was evident in the face-to-face interviews, as participants pointed out specific muscles or skin characteristics as they talked. Various non-verbal communication techniques provided an added dimension to the face-to-face interviews, and at times served as prompts for further questions or probes by the researcher. Intonation and facial expressions also provided a clearer understanding of the meaning of statements made by various face-to-face participants. An advantage to email interviews is that the time between interactions allows thoughtful follow-up to questions posed (Hamilton & Bowers, 2006; Holmes, 2009; McAuliffe, 2003). Use of these two data collection methods contributed to providing a rich description of the physical changes experienced by persons aging through the middle age years with a traumatic incomplete SCI.

### **Data Management and Data Analysis**

As soon as data were collected through the first interview, procedures for managing and analyzing that data commenced (Hsieh & Shannon, 2005). The unique code number assigned to each participant in the recruitment data log was used to label all of that participant's data for the purpose of de-identification. Demographic data was entered by the researcher and analyzed via Microsoft Excel to yield appropriate descriptive statistics. These statistics were used solely for describing the study sample.

Audio recordings of each face-to-face interview were professionally transcribed verbatim into a Microsoft Word document. Audio recordings and Word documents were identified by code number only. The researcher and the transcriptionist exchanged data files in person via an encrypted USB portable drive. The researcher checked each transcript against the audiotape to ensure accuracy and to mask any identifying data.

Data from the email interviews did not require transcription. This has been cited as another advantage to email interviews over taped interviews, due to both decreased transcription costs and the elimination of potential transcription errors (Ahern, 2005; Hamilton & Bowers, 2006; Holmes, 2009). All text from email interviews was copied and pasted into a Word document by the researcher. All Word documents containing interview data (from both face-to-face and email interviews) were de-identified, labeled with the participant's code number only. The log linking names to identification codes was kept in a locked drawer in the researcher's office.

Qualitative content analysis was employed to summarize and analyze the interview data. Qualitative content analysis is recommended for QD studies (Hsieh & Shannon, 2005; Sullivan-Bolyai et al., 2005). The researcher read each interview transcript in its entirety several times as it was received. This allowed the researcher to "obtain a sense of the whole" (Graneheim & Lundman, 2004, p. 108) and promoted an understanding of the contextual meaning of the interview data, an important hallmark of qualitative content analysis (Hsieh & Shannon, 2005). Following these initial readings, the researcher read the interview transcript and highlighted specific words or phrases that represented key concepts and themes. These concepts and themes provided the foundation for determining data codes (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). Field notes from each face-to-face interview were read and considered in

conjunction with the interview transcript, which assisted in clarifying meanings and identifying themes (Creswell, 2003).

As the data were analyzed, there were several occasions when the researcher needed to re-contact a participant to clarify a statement. Each participant was asked at the conclusion of their interview to grant permission for a potential follow-up contact after conclusion of the interview. This follow-up was done via email at the request of each participant. Data from follow-up contacts made via email were managed in the same manner as initial interview email data.

All interview data was coded in chunks as descriptive themes arose from the content of the interviews. Numbered text segments related to each code were copied and pasted into Word documents. As more interviews were completed, data from each was compared to previous interview data. The expectation with qualitative content analysis is that the codes will be significantly modified through the iterative analytic process as new data is introduced (Ayres, Kavanaugh, & Knafl, 2003; Hsieh & Shannon, 2005; Miles & Huberman, 1994).

A hallmark of QD is staying close to the data, with minimal interpretation by the researcher (Sandelowski, 2000). Some themes that emerge may link back to the theoretical framework, while others may not (Sandelowski, 2010). As data were collected and analyzed, the data collection process was re-shaped to allow for more rich description of emerging themes (Richards & Morse, 2010), whether or not those themes reflected ideas in the theoretical framework. For example, questions and probes were altered to elicit increasingly rich description of emerging themes in participants' transition experiences.

The process of identifying themes from codes was chronicled by the researcher in a password-protected electronic journal. This journal provided an audit trail to support

trustworthiness. The researcher's dissertation chairperson and methodologist periodically reviewed text segments and codes to ensure accuracy and support trustworthiness (Graneheim & Lundman, 2004).

### **Trustworthiness**

Regardless of the specific research methodology that shapes a study, researchers must adhere to certain "standards of quality" (Creswell, 1998) or methodological rigor (Tobin & Begley, 2004) in their science. Within the broad scientific community, research findings are examined in terms of reliability and validity (Morse & Richards, 2002). Reliability is generally associated with repeatability, while validity is a complex idea that addresses the truth or accuracy of a claim (Burns & Grove, 2005). Both of these concepts are clearly grounded in a positivist framework, and thus many argue that there is no place for these concepts in a naturalistic paradigm (Sparkes, 2001; Tobin & Begley, 2004). Lincoln and Guba (1985) proposed an approach to rigor within the naturalistic paradigm that was encapsulated under the term *trustworthiness*. This seminal work identified new criteria for the examination and maintenance of rigor in naturalistic studies that parallels the criteria for conventional, quantitative research (Sparkes, 2001). The components of Lincoln and Guba's (1985) approach to trustworthiness are credibility, transferability, dependability, and confirmability.

*Credibility* is akin to the conventional criteria of internal validity (Lincoln and Guba, 1985). Credibility examines the "representativeness" of the findings (Cutcliffe & McKenna, 1999); if the researcher's interpretations "fit" the view of the participants, then the findings are deemed credible (Tobin & Begley, 2004). Lincoln and Guba (1985) detail a number of strategies to promote credibility, including prolonged engagement, peer debriefing, negative case analysis and member checks. Prolonged engagement involves a significant investment of time on the part

of the researcher, immersing in the context of the phenomenon under study (Lincoln & Guba, 1985). Face-to face interviews were scheduled for two hours, allowing for adequate time to be spent with each participant, and avoiding premature closure. If a participant had shown signs of fatigue, the researcher would have ended the interview, and scheduled a follow-up face-to-face or email interview to ensure the comfort of the participant and prolonged engagement. However, no participants showed signs of fatigue during any face-to-face interview.

Peer debriefing "provides an external check on the inquiry process" (Lincoln & Guba, 1985, p.301). The researcher's dissertation advisor and methodologist served as both sounding boards and protagonists to help clarify the researcher's interpretations, thus supporting credibility (Granheim & Lundman, 2004). A QD study is very amenable to this strategy, as there is generally adequate time between interviews, when data coding and analysis are being done, to solicit appropriate debriefing.

The strategy of member checking has been identified as "the most crucial technique for establishing credibility" (Lincoln & Guba, 1985, p.314). This involves presenting the findings to some members of the study population to verify their agreement (Cutcliffe & McKenna, 1999). This process can occur at multiple times throughout the research process. Informal member checks take place within the confines of an interview, immediately allowing clarification. The ability to clarify a participant's meaning is facilitated by the email interview format (Ahern, 2005; Beck, 2005; Hamilton & Bowers, 2006; Murray & Fisher, 2002). Formal member checks often occur toward the end of a study, when more solidified findings are shared with representatives of the study population (Lincoln & Guba, 1985). One of the major difficulties with formal member checking is that some participants do not recognize their own experience once it is interpreted by the researcher, and therefore they cannot verify the findings (Cutcliffe &

McKenna, 1999). One of the ways to address this difficulty is to "use the actual words of the participants" (Cutcliffe & McKenna, 1999, p.378), a practice that is highly valued in the QD tradition (Sullivan-Bolyai et al., 2005). Member checks were performed after the data were analyzed to ensure that the emerging themes are reflective of the experience of aging with an incomplete SCI. Each participant was asked for permission to follow-up by email or telephone to perform member checks within twelve months of data collection, and two participants were asked to perform member checks. Both of these participants chose to participate in the member checks by telephone. Each of them affirmed the themes and subthemes that had arisen from the data, lending credibility to the study findings.

Lincoln and Guba's (1985) criterion of *transferability* is reflective of the positivist concept of external validity, although the concepts are notably different, due to the heavy emphasis on context in the naturalistic paradigm. Transferability, or generalizability, requires that another researcher, using the same data, would reach the same conclusions. In many ways, this is inconsistent with the naturalistic tenets (Tobin & Begley, 2004). According to Lincoln and Guba (1985, p.316),

the naturalist cannot specify the external validity of an inquiry; he or she can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility.

The emphasis on thick description perhaps aligns the potential for transferability more with an ethnographic approach, but the compilation of a full, rich data base in this QD study potentially enhances transferability as well.

*Dependability* as a criterion parallels the positivist concept of reliability, while *confirmability* is comparable with objectivity, or neutrality (Tobin & Begley, 2004). Lincoln and

Guba (1985) emphasize that each of these parameters should be demonstrated separately, however, the recommended means for confirming both of these criteria is the examination of an audit trail. An audit trail is a compilation of documents including transcripts, field notes, methodological notes, and analytical documentation (Lincoln & Guba, 1985). In this study, an audit trail was maintained, and the dissertation chair and methodologist served as independent, knowledgeable evaluators to review the documents. Also included in this audit trail is the researcher's reflexive journal, detailing her personal feelings, biases, reasoning, and reactions throughout the research process (Smith, 1999).

### **Reflexivity**

The concept of reflexivity requires the qualitative researcher to acknowledge her perceptions and values in order to make explicit any potential impact that these might have on data collection and analysis (Cohen & Crabtree, 2008; Lambert, Jomeen, & McSherry, 2010; McBrien, 2008). This is not simply a one-time acknowledgement, but an ongoing self-appraisal throughout the study (Koch, 2006; McBrien, 2008).

The researcher has a longstanding personal interest in the research topic, motivated by a family member who is living with an incomplete SCI. During the study, the researcher's self-awareness was facilitated by keeping a reflective journal of personal thoughts and emotions that arose (Lambert et al., 2010; McBrien, 2008). Entries were made immediately following each face-to-face interview, when each completed email interview closed, and as thoughts occurred during data analysis. In addition, routine debriefing sessions with the dissertation committee chair helped to reveal any implicit thoughts and emotions that may have distracted the researcher from the themes emerging from the data (Cohen & Crabtree, 2008).



## **Protection of Human Subjects**

Prior to implementing the study, IRB approval was obtained from the University of Massachusetts Medical Center IRB where the researcher is enrolled in doctoral studies. The NESIC/Boston Medical Center IRB determined that they were classified as "not engaged" in this project, and thus were willing to distribute the recruitment materials based upon the study's UMass Medical Center IRB certificate. Informed consent was obtained from each participant prior to commencing the initial interview, including the possibility of follow-up contact, either in person or via email. A discussion of the informed consent was recorded and transcribed before each face-to-face interview, and re-affirmed upon any subsequent contact. The consent included permission to re-contact the participant for clarification and/or member checks. The participant was ensured of the right to withdraw from the study at any time prior to its conclusion. In that case, the data gleaned from his or her earlier participation was retained.

A Fact Sheet clearly stating the purpose of the study and expectations for participants was provided electronically for all potential email interview participants (Appendix H). Email confirmation from the participant of the receipt of this document, coupled with the participant's submission of responses to the interview questions, implied consent to participate in the research study (Cantrell & Lupinacci, 2009; Holmes, 2009). Again, the right to withdraw from the study at any time was emphasized. In fact, the on-line interview environment makes withdrawal from the study easier for a participant who does not wish to continue (Holmes, 2009). Two participants discontinued their email responses before their interviews were complete, and these interviews were administratively closed. Neither of these participants indicated any distress prior to discontinuing their responses. The researcher sent follow-up emails, and one of these participants was no longer accessible via her email address. The other participant simply

stopped responding to additional interview questions. Data obtained through these interviews were retained, as planned.

Although distress related to participation in this study was not anticipated, participants were encouraged prior to the interview to make a note of whom they could talk to if they did feel any distress. In face-to-face interviews, this encouragement was given orally as the interview commenced. The researcher was cognizant of any visible signs of distress, and would have discontinued the interview if the participant wished. For email interviews, as qualitative data collection began, participants were encouraged to make note of a support person who would assist them if they experienced distress. The researcher would have immediately sent a participant an email statement re-affirming the importance of contacting a person with whom the participant could talk upon receipt of any email indicating possible distress. As with all email communications only the researcher had access to the email to maintain confidentiality.

In the transcription process, all interview data were identified by the unique numerical code assigned by the researcher during recruitment (Morse & Richards, 2002). Pseudonyms were inserted to mask any names recorded during the interview. Recordings and transcripts were stored in the researcher's password-protected computer. Email communications were received in the researcher's password-protected email account. The text of the interview responses were cut-and-pasted into Word documents, deleting or masking any identifying information or names that may have been embedded in those emails, and then the emails were deleted (Hamilton & Bowers, 2006). These Word documents were identified by numerical code only, and no email addresses or other identifying information was retained in the documents. Hard copies of transcripts or web interview responses are stored in a locked file in the researcher's office and on

her password protected computer. The researcher will destroy these documents 5 years after dissertation defense.

As an expression of gratitude for participation, each participant was offered one prepaid gift card for 25 dollars for completing the study. Two participants declined the gift card, stating that they preferred to donate their time to support the research project. Any additional contact with a participant for the purposes of clarification or member checking was acknowledged by a written note of thanks, but gift cards were limited to one per participant.

## Chapter 4

### Results

Qualitative Descriptive methodology was used to uncover the changes in physical function experienced by individuals transitioning through middle age with a traumatic incomplete spinal cord injury. Participants described a variety of changes in different body systems, as well as a lack of change in some body systems as they have gone through their middle years (Aim 1). Participants also described the timing of those changes (Aim 2). They identified past and present sources of information about changes in physical function experienced through middle age (Aim 3).

As the data analysis progressed, a rich description of the transition through middle age with an incomplete SCI emerged. Three themes were identified in the participants' descriptions of their experiences of changes in physical function through their middle years. The remainder of this chapter provides a rich description of these themes. The participants described the uncertainty of *travelling through uncharted territory* as they age through their middle years with limited knowledge or anticipatory guidance about aging with an incomplete SCI. They also described their *strategies for living in uncharted territory*. This theme includes three sub-themes. Among these, the participants described the importance of *being vigilant* in their day-to-day self care. They also described the challenge of trying to understand their changes in physical function, or *figuring it out*. In addition, the participants emphasized the importance of *staying positive* as a strategy for living in uncharted territory. The final theme described by the participants was *recognizing the impact of changes*.

This chapter begins with a description of the study participants and the data set. Then, the results are briefly presented by specific aim, followed by the themes and subthemes arising from the analysis.

### **Participants**

A total of 36 individuals volunteered to participate in the study, and 17 of these individuals met the inclusion criteria and were enrolled as study participants. All data were gleaned through self-report. The majority (n = 10) of the participants were New England residents. However, participants from other geographic locations also responded to the emails from the NERSCIC or the GBC, and participated via email from the Western United States (n=2), the Southern United States (n=2) and Europe (n=1). Snowball sampling also yielded two additional participants from the Western United States. Participant demographic data are presented in Table 5.

Table 5

*Participant Demographics*

	Face-to-Face (n=6)	Email (n=11)	Total (N=17)
Age (years)			
Mean	52	52.8	52.5
Range	46 - 65	35 - 61	35 - 65
Standard Deviation	6.2	7.0	6.7
Gender			
Male	3	5	8
Female	3	6	9
Education			
Some college	1	2	3
College graduate	3	6	9
Master's degree	2	3	5
Race - White	6	11	17
Marital Status			
Married	2	7	9
Single/Divorced/Widowed	4	4	8
Age at Time of Injury			
Mean	17.3	26.8	23.5
Range	16 - 20	16 - 41	16 - 41
Standard Deviation	1.5	8.4	8.2
Duration of Injury (years)			
Mean	34.7	26	29.1
Range	28 - 45	16 - 36	16 - 45
Standard Deviation	5.9	7.7	8.1
Level of Injury			
Cervical	5	9	14
Thoracic	1	2	3
Ambulatory Status (post-rehabilitation)			
Ambulatory	2	5	7
Non-ambulatory	4	6	10 <sup>a</sup>

<sup>a</sup> 1 participant did not report ambulatory status, but descriptions given would indicate that he was non-ambulatory since his traumatic injury. He is included in this count.

The participants ranged in age from 35 to 65 years (mean age = 52.5; median age = 52). Their injury durations ranged from 16 to 36 years (mean DOI = 29.1 years; median DOI = 30 years). Twelve participants were injured in motor vehicle accidents, and three sustained their SCI from diving accidents and two from ladder falls. The majority of the participants (n=14) described cervical level injuries, while the remainder (n=3) had low thoracic injuries. Seven participants reported being at least partially ambulatory since their SCI, and nine reported that they have required a wheelchair since the time of their injury. One participant did not directly comment on his ambulatory status, but other data from his interview suggest that he was unable to ambulate post-injury.

Eight of the participants were male and nine were female. All of the participants described their ethnicity as White and/or Caucasian. When asked to describe their marital status, nine participants stated that they were married, five were single, two were divorced and one was widowed. The participants were well-educated; three reported completing some college, nine were college graduates, and five had Master's degrees. Ten of the participants reside in the Northeastern US, while the others live in the Western US (n=4), the Southern US (n=2) and Europe (n=1).

In addition to the demographic data that were directly collected, participants also shared information about their employment status. Thirteen participants were employed at least part-time, one was on disability but actively seeking employment at the time of the interview, and two others described their work as being in a volunteer capacity. One described herself as "able to not work due to an accident settlement."

## **Comparison of Participants by Interview Method**

Six participants selected a face-to-face interview, and 11 participated via email interview. No substantive differences were noted between the participant characteristics in these two groups. The six face-to-face participants ranged in age from 46 to 65 years with a mean age of 52 years (median age 51 years), while the email participants were age 35 to 61 year (mean age 52.8 years; median 53 years). The injury duration for the face-to-face participants ranged from 28 to 45 years with a mean DOI of 34.7 years (median 35 years), which is slightly longer than the email participants' mean DOI of 26 years (range 16 to 36 years; median 26 years). The most notable difference between the two groups was the participant age at the time of injury, which was younger for the face-to-face group (mean age of 17.3) than the email group (mean age of 26.8). The face-to-face group included three females (50%), while the email group included six females (55%). Two of the face-to-face participants (33%) and five of the email participants (55%) were able to ambulate following their injury. One face-to-face participant (16%) and two email participants (18%) reported a low thoracic SCI. The two groups are reflective of the characteristics of the total study sample.

## **Description of the Data Set**

The data set was comprised of verbatim transcripts of 17 interviews. The six face-to-face interview transcripts captured interviews that ranged in length from 50 minutes to 95 minutes. In addition to the transcribed interviews, the researcher documented field notes immediately following each face-to-face interview. These notes included observations of non-verbal communication such as gestures or facial expressions, as well as notations of statements made after the audio recording had been discontinued. These field notes were included as part of the data set.



Transcripts of the 11 email interviews varied in length and detail. Email participants were encouraged to respond whenever it was convenient, and thus the elapsed time for these interviews ranged greatly from one week to 13 weeks. Two of the email interviews were administratively closed by the researcher when they were nearly, but not fully, complete. One was closed after partial data collection when the participant stopped responding to the research questions over a period of six weeks, which included four attempts at contact. The researcher sent an email closing the interview, and asking for the participant to provide an address in order to send a thank you letter and gift card, but the participant did not respond. In the second case, the interview was closed when four successive emails over six weeks were returned as undeliverable. Because the researcher has no other contact information, she could not send this participant notice of closure or the thank you letter and gift card. Data collected prior to administrative closures were included in the data set.

The face-to-face transcripts were generally much longer than the email interview transcripts, which initially might appear to indicate that there was greater depth in the face-to-face interviews. However, further reflection on the data set revealed that while there was a difference in the number of words used, there was not as great a contrast in content as the word count might reflect. The face-to-face interview transcripts included a significant amount of conversation that was not directly focused on the interview. Some of this might be due to the inexperience of the interviewer, and the lack of adequate verbal direction offered to the participants. The face-to-face interviews also contained a significant amount of repetition of information from the participants, perhaps due to the fact that they were “thinking aloud” as they responded immediately after the questions were posed. In contrast, the email transcripts contained much less “chatting” interaction. Responses from the participants were generally

succinct and focused on directly answering questions from the interviewer. The email interviews allowed for the participant to respond to questions at their convenience. This made it possible for participants to reflect on the questions posed and craft an answer without the documented “think aloud” being included in their response.

The researcher reviewed the verbatim transcripts that comprise the data set, and masked any identifiable information. For example, names were masked, as well as specific locations, including hospitals or rehabilitation centers (see data de-identification process described in Chapter 3). The transcripts were then left unaltered for the analysis. However, obvious typographical errors in the email transcripts were edited in data presented in this report.

### **Aim 1: Identification of Physical Changes**

Each participant was asked to identify how his or her physical function has changed in the time that the participant reported as middle age years. Participants described a variety of changes in physical function (see Table 6).<sup>1</sup>

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<sup>1</sup> Throughout this dissertation, specific numeric counts are reported to facilitate future use in a meta-synthesis (Thorne, Jensen, Kearney, Noblit & Sandelowski, 2004) and are not intended to imply generalizability.

Table 6

*Reported Changes in Physical Function*

Type of Change reported by participants (N=17) <sup>a</sup>	Participants reporting changes in middle years	Participants reporting no changes in middle years
Decreased Muscle Strength	14	1 <sup>b</sup>
Weight Gain	11	4
Decreased Endurance	10	2
Wear and Tear	10	0
Bladder Changes	8	7
Bowel Changes	5	11
Falls/Balance	5 <sup>c</sup>	4
Skin	4	2
Spasticity	4 <sup>d</sup>	0
Sexual Function	3	2

<sup>a</sup> Not all participants mentioned each of these categories.

<sup>b</sup> 1 participant reported either no change or an increase in strength

<sup>c</sup> 4 reported an increase in falls/decreased balance; 1 reported fewer falls

<sup>d</sup> 3 reported an increase; 1 reported a decrease in spasticity

## **Decreased Muscle Strength**

The physical change that was most commonly cited by the participants was a decrease in muscle strength and/or an increase in muscle weakness. Participants used these terms synonymously, and they are combined in this data analysis. Fourteen participants reported a decrease in strength and/or an increase in muscle weakness in their middle years. Participants described overall loss of strength as well as decreased strength in specific muscle groups. The most commonly identified muscle weakness was in the legs (n=5).

## **Weight Gain**

Weight gain was another commonly cited physical change. Eleven participants identified that they have gained weight in their middle years. This was closely tied to other changes as well. As one participant expressed:

I know when you get in your forties and you have changes, changes in your metabolism and whatever, you got weight gain, that definitely contributed to me slowing down - that changed my level of function. So I, I, what I could do at 21, I can't do at 41.

Several other participants also linked weight gain to decreased endurance (n=4).

## **Decreased Endurance**

Ten participants described a decrease in endurance through their middle years. This was manifested in statements such as “I am older so I like a bit more time to rest... my endurance cannot maintain like it used to.” Another participant linked strength with endurance, stating “muscle strength and endurance have definitely decreased. I have to consciously limit my activities when planning my schedule so I don’t overload myself. I am definitely less active than I was.”

Five of the seven participants who were able to ambulate after their injury reported decreases in endurance manifested by increased fatigue when walking and subsequently walking less. As one of these participants stated:

I notice the lack of endurance in the distance that I can walk before I need to sit and take a break. Within a couple of years after the injury, I was able to walk quite some distance. Now, I am on the verge of using a cane to assist in the longer distance walking.

In contrast, two participants stated that they have not experienced any change in their endurance during their middle years.

### **Wear and Tear**

Ten participants identified “wear and tear” changes in their middle years. These changes were described in the shoulders (n=7), back (n=3), neck (n=2), leg (n=1), knees (n=1), elbows (n=1) and wrists (n=1). Eight of these participants specifically described pain as a manifestation of wear and tear changes, particularly in their descriptions of wear and tear changes in their shoulders and neck. Six of the eight participants describing shoulder and/or neck wear and tear have been wheelchair users since their initial injury and the remaining two participants currently use a wheelchair full-time, although each of them was able to ambulate with braces and crutches after their SCI.

### **Bladder**

Another area of physical change identified was bladder function. Eight participants indicated changes in bladder function, while six indicated that they have experienced little or no change as they have gotten older. Of those reporting bladder changes, four indicated that their

changes were improvements in bladder function due to a change in bladder management strategies as opposed to changes related to aging, with two of them reporting insertion of a suprapubic catheter during their forties, one reporting a bladder augmentation surgery in her forties, and another reporting her choice to begin to utilize an indwelling catheter in her forties rather than continue to respond to bladder spasms as she had done previously. She describes this choice:

I have an indwelling catheter and love the freedom. All of the years before [age 47] I had to hurry to the bathroom whenever my bladder would spasm, which was every 45 minutes or so, so I had to be near a bathroom, or if I was in the car, pull over and jump on a fracture pan, or with friends, I would say "stat" and they would help me get on and empty it for me.

Four participants reported changes in bladder function that were not due to changes in bladder management strategies. Without attribution, three participants cited an increase in urinary tract infections in their middle years. Other changes were increased incontinence (n=2), and more bladder spasms (n=1).

## **Bowel**

When the participants were asked to identify changes in physical function, the most commonly discussed body system was the bowels; however, 11 participants who mentioned bowel changes specifically stated that they have *not* experienced changes in their middle years. The five participants who reported bowel changes all cited constipation. As one participant stated, "I think it's a combination of getting older and SCI. My system has slowed down and my

bowel routine takes longer.” Additionally, one participant reported an increase in bowel “accidents” in her middle years.

### **Other Changes in Physical Function**

Other changes in physical function that were identified by the participants include falls/balance, skin, spasticity and sexual function. Four participants indicated that they have fallen more frequently during their middle years, while one reported a decrease in falls, and four others noted no change in the frequency of falls they experience. Four participants described skin changes in their forties. These changes included slower healing and an increase in skin breakdown due to decreased activity or changes in equipment (e.g. skin irritation from inconsistent use of leg braces). One participant described an increase in skin breakdown due to spasticity, which caused rubbing against her leg braces. In contrast, another participant reported that his increased skin breakdown was a result of a decrease in spasticity, which limited his movement and thus contributed to increased unrelieved pressure on his coccyx.

Three of the male participants described changes in sexual function. One reported an indirect change related to fatigue, one reported that “things take longer” and “things get smaller”, and another participant reported severe post-ejaculation headaches. Of the nine women participants, five reported that they have experienced menopause or are currently experiencing menopausal changes, while one had a hysterectomy during her middle age years. None of these participants associated menopausal changes with their SCI.

### **Aim 2: Timing of Physical Changes**

As the participants reflected on their changes in physical function, they described most of those changes as gradual. When they were asked to identify a time frame for those gradual

changes, they offered a range of descriptions. Participants stated that the physical changes began in their late thirties (n=2), at age 40 or in their early forties (n=7), age 45 or middle forties (n=2), late forties (n=2), and age 50 (n=3). Thus, many changes in physical function associated with aging through the middle years began in the early to middle forties. The gradual changes in physical function were evident in their description of wear and tear changes, with statements such as “the muscles just wouldn’t take the abuse anymore” and “[my leg has] taken a beating...it’s just worn out.” Others described a gradual decline in strength and/or endurance that was more visible in retrospect than in the midst of the change. As one participant shared:

It just all progressed and I, I look back, you know... it just wasn't one incident that caused me to stop walking, it just slowly, and I didn't even realize it. It's just been something gradual - - and I never, I didn't even see it happening.

While most of the participants described gradual changes in physical function, five participants also described specific critical events that they associated with changes in physical function. Two participants identified specific injuries (one knee injury and one hip injury) that they believe lead to decreased strength and decreased endurance. Two participants described acute illness they did not attribute to their SCI, but they identified changes in physical function that resulted from that illness, particularly that they never regained their full strength. Another participant described that she never fully regained her strength after a long hospitalization for a surgical bladder augmentation and a subsequent bowel obstruction. One participant identified an abrupt change in physical function in his late fifties, stating that “after 33 years of severe spasticity, almost overnight, the spasticity almost totally disappeared except for short periods when it kicks in.”



Three participants compared the timing of their changes in physical function to aging in able-bodied individuals, perceiving their own changes as accelerated due to their SCI. As one participant stated, “In general I feel due to the SCI my body is 20 years older than my actual age [mid-50’s] and I am dealing with issues most don’t have to address until they are in late 70s & early 80s.” Another participant said, “Supposedly internally our bodies age quicker because of the spinal cord injury and if that’s the case, ok, that would explain why I’m havin’ the bowel issues late forties and early fifties when that tends to be sixties for some people.”

### **Aim 3: Sources of Information**

Participants were asked to describe their anticipatory knowledge and preparation for any changes in physical function they have experienced as they age, including their past or present sources of information for that knowledge. Table 7 includes the various information sources they cited.

Table 7

*Identified Sources of Information about Aging with SCI*

Information Source	Number of participants mentioning
Websites	7
Christopher and Dana Reeve Foundation	1
Craig Hospital	1
Disaboom	1
Mayo Clinic	1
NIH	1
NSCIA	1
Rutgers Care Cure	1
Spinal Network Mobility	1
Stepping Forward-Staying Informed/BMC Webinar	3
“Internet searches”/Google	3
Health Care Providers	3
Peers/Support Group	3
Reading research/Library	3
Professional Contacts in SCI Field	2
Stepping Forward Staying Informed Conference <sup>a</sup>	2
Paraplegia News	1

<sup>a</sup> Four participants mentioned this annual conference, but only 2 stated that they had attended.

### **On-line Information Sources**

The most common (n=7) source of information identified by the participants was internet websites. (Table 7 lists the specific websites that were cited.) Several participants named more than one website, but none of the specific websites were identified by more than one participant, with the exception of web-based information from Boston Medical Center's Stepping Forward-Staying Informed Consumer Education Program, including the opportunity to access webinars through this program (n=3). Three other participants described using Google or performing internet searches to glean information about aging with an incomplete SCI.

### **Health-Care Providers as Information Sources**

Three participants acknowledged their personal health care providers as a source of information in addressing current changes they are experiencing. Three other participants work directly in the healthcare field with other individuals with long-term disabilities, including SCI, and two of these participants mentioned that their work colleagues are an occasional source of information for them in terms of preparing for physical changes. One participant indicated that one of her health care providers had told her to anticipate a decline in her ability to ambulate. "I was told by an orthopedist that I couldn't expect to walk forever. He said, 'You're getting older.'" In contrast, ten of the participants indicated that they received little to no information from their health care providers in the past about what they might expect in terms of changes during their middle years.

### **Other Information Sources**

Another reported information source was reading research reports or visiting a library (n=3). One participant specified that he subscribes to *Paraplegia News*, a print journal published

by the NSCIA. Two participants mentioned attending and gaining information from the annual Stepping Forward Staying Informed Conference, a regional conference for SCI consumers, caregivers and providers. Two other participants mentioned this conference as a potential information source, but they have not attended the conference. Three participants identified peers or disability support groups as information sources.

### **Summary of Results by Specific Aim**

Participants described a variety of changes in different body systems. There were some commonalities noted across many participants, particularly in their descriptions of their experiences of decreased muscle strength, decreased endurance, weight gain, and wear and tear. These changes were described by both male and female participants, as well as by both ambulatory and non-ambulatory participants. There was also variation across participants, as a number of changes (such as changes in bladder and bowel function, occurrence of falls, skin changes, spasticity, and sexual function) in physical function were described by only a few of the participants. Participants described the timing of their changes in physical function primarily as gradual. They identified some past and present sources of information about changes in physical function experienced through middle age. The internet was the most common source of information, but there was little overlap in the specific websites mentioned by the participants. Health care providers were notably described as having little if any information to share. Overall, participants emphasized their lack of knowledge about anticipated changes in physical function through middle age.

As the analysis of the participant data progressed, a rich description of participants' transition through middle age with a traumatic incomplete SCI emerged. Three themes of

transition with informational redundancy were identified in the participants' descriptions of their experiences of changes in physical function through their middle years. The following sections describe each of these themes.

### **Travelling through Uncharted Territory**

As participants described their changes in physical function through middle age, the theme of *travelling through uncharted territory* clearly emerged. Participants expressed that they felt a lack of preparation and guidance in facing the changes of aging, experience which can be likened to travelling without a map. As one participant said, "Being aware of potential changes is extremely important." He went on to say that without that information, "You really do not know where you are headed. It is like travelling through uncharted territory."

Most of the participants shared that they had entered their middle age years without any particular anticipation of changes in physical function they might experience. Only one participant verbalized her expectations; specifically, that she would continue to ambulate with the same ability as she achieved post-injury. She was surprised by the changes in physical function she experienced as she reached middle age that resulted in the loss of her ability to ambulate. As she said, "It's amazing - I really didn't think that this was gonna happen, I thought I was, would walk, just keep walking...."

Many of the participants described the uncertainty associated with the physical changes they had already experienced and other changes that might be forthcoming. Several participants made statements such as, "I've never been told anything about aging with a SCI and what to expect." Ten participants stated that they wished they had been given more information about what kinds of changes in physical function to expect. Only one participant indicated that he had

access to any information that he wished to have about the changes in physical function he might anticipate in the middle age years. This participant works directly in the healthcare field in a SCI center, and therefore stated that he has knowledge resources readily available.

Participants indicated that the lack of anticipatory information began during their immediate post-injury period. Several participants stated that they were injured at a time when long-term survival after SCI was not expected, so they had not received any guidance during their acute rehabilitation or early years with a SCI that focused on aging changes. As one participant said, “They were thinking, you'll probably make it to 38, don't expect to see 40, if you do, consider yourself lucky.” Another participant echoed that thought, saying:

I really wish I had been taught what to expect, but honestly, back in the 70's not many persons with a SCI lived very long, go figure...I have never been told by anyone in my 37 years [post-injury] what to expect.

Seven of the participants specifically stated that they continued to receive little to no guidance or information from their current health care providers about the changes in physical function that they are experiencing or might experience in middle age. As five participants clearly stated, “They just don't know.” When one participant was asked what anticipatory guidance he had received about aging with a SCI, he stated, “Really not much from any health care professional. I am not sure they know how quickly or to what extent the changes will occur. I feel like I have to find most of my information on my own.”

Many participants expressed a desire to have information about what to expect, rather than being “taken by surprise” with changes in physical function as they age. As one participant stated:

Have I ever been part of ... a discussion about what to expect aging with spinal cord injury? I don't recall. I think it's a marvelous idea. I [get information about] aging in general, but not necessarily aging with a spinal cord injury, which obviously has a different effect. It would be great to say 'Here's what to expect if you're injured at a certain age and, and how many years post injury,' so that you could potentially avoid whatever issues those are at the milestone.

This man was one of several participants who desired more anticipatory guidance for the expressed purpose of avoiding potential changes or managing changes. This leads to the second theme which arose from the data, *strategies for living in uncharted territory*.

### **Strategies for Living in Uncharted Territory**

The lack of information and anticipatory guidance about the changes in physical function through middle age appears to be a driving force behind participants developing their own strategies for self-assessing, managing and understanding changes as they aged. Several participants expressed the importance of “living one day at a time” and “dealing with things as they come.” As one participant said, “I find that I just need to stay on top of things – I need to listen to what my body is telling me, and then respond accordingly.”

Three subthemes were identified in the participants' descriptions of their experiences. These were *being vigilant*, *figuring it out*, and *staying positive*.

#### **Being Vigilant**

A subtheme that arose in all 17 of the interviews was the idea of *being vigilant*, or being attentive to one's body on a day-to-day, moment-by-moment basis. As one participant stated,

“When you have a spinal cord injury it’s really a full time job. You know, you can’t, you just can’t take a break, and you can’t ignore the signs...you have to be vigilant.” *Being vigilant* can be likened to the need to pay close attention to cues when travelling without a map. This attentiveness was described as an essential part of managing physical changes that come with middle age and in preventing possible complications. Participants described the importance of being vigilant in various focal areas, including the bowel, skin health, bladder/urinary tract function, and weight changes.

**Vigilance in bowel care.** One specific context where participants emphasized the need to be vigilant was managing changes and preventing possible complications in bowel function. Five participants described changes in their bowel function in their middle age years, including an increase in constipation and bowel incontinence. As one participant reflected on his changes in bowel function through his forties, he stated:

Oh, the bowels! The late forties on has been not as good ... needing to use more suppositories, a lot more digital stimulation, having to actually take assorted laxatives like Sennas. Um, never used to have to do any of that...I’m kinda bowel obsessed now, making sure I don’t get constipated or I don’t have the involuntaries. It’s like, uh, can’t eat this, gotta eat that, and, um, which day should I do that...readjusting everything.

He went on to describe in great detail various “trial and error” experiences with specific foods that he uses to maintain his bowel function. He adjusts his diet regularly based on his bowel function. Another participant contrasted his current bowel function in middle age to his experiences as a younger man:



I have to be more careful about what I eat, and that would be if uh, I could throw down a box of raisins twenty years ago, that box of raisins is gonna have to be cut in half...I do notice with the bowels, if I could eat ten cookies and not have an issue ten or twenty years ago, I could have an issue now...I think as you age with a spinal cord injury, your bowel...care require(s) more oversight, which is possible, that's not to say that you don't have the urge once in a while to put, put away a sleeve of, uh, Girls Scout cookies, uh, but at age 51, it may not be as easy to recover from that as at age 21.

This participant demonstrated the theme of vigilance, emphasizing the need for “more oversight” in dealing with his bowel function, stating that, in spite of the aging changes, his bowel function is “still very manageable.”

Several (n= 11) participants stated that they have not had significant changes in their bowel function through their middle age years. Many of them (n=10) emphasized that the lack of bowel changes was due to their vigilance in preventing complications, particularly through their diet. This was reflected in statements such as “being aware of what I eat helps with control” and “I have learned to be a careful eater over the years.” One participant specifically expressed her ability to avoid bowel issues by eating “a healthy fiber rich diet”. Another participant emphatically stated that she has not seen any bowel changes with aging, and does not anticipate any changes. Her comments reflect the theme of vigilance, as she stated, “Not gonna happen – especially with my bowels. I can control that and so, I've always sorta paid attention. I think when you don't pay attention that's when you get into trouble.”

**Vigilance in skin care.** Another specific focus where participants emphasized the need to be vigilant was related to changes in the skin. Several (n=6) participants emphasized the

importance of being very attentive to any possible skin complications, particularly as they age. As one participant stated, “My skin has been good but I do know that it gets thinner as you age so I try to be more vigilant in its assessment.” Another participant, who has experienced ongoing pressure sores, talked about his strategies for preventing more skin breakdown:

I keep my weight at a reasonable level even though I could lose fifteen plus pounds now. I think keeping weight at a reasonable level is huge to avoid pressure sores and you see that in all the medical documentation, uh, but it is key to, uh, to heed that advice. I've had pressure sores on my left ankle which I had, uh, probably 11 years ago when I was, uh, 41, uh, and that developed, uh, that, I mean I should have picked it up but also it was just very slow developing and I had a sore that unfortunately landed me in the hospital for a coupla weeks... I have had a sore on elbows because I lean a lot. Uh, like I'm doing now. And I've had sores on both elbows, uh, with, you know, with infections at the same time, uh, I check my skin on a regular basis, my wife assists me with that, and hopefully that's not big, large issues.

Another participant talked about “battling skin issues” since he was in his forties. He described a careful diet as an important part of this battle, stating, “Take the Vitamin C’s, take the Vitamin E’s. Eat high protein foods, um, ‘cause they’re good for your skin, so been doin’ that.” One participant emphasized the importance of being attentive to equipment that is designed to help reduce skin issues as well as being vigilant when skin issues arise:

You have a back-up [seat] cushion, make sure you know your skin, your surface, my shower chair is padded. If it starts to get hard I get a new one, you know I'm vigilant. Have to be... I get a red mark, I have a scar from my only skin breakdown when I was a

teenager and that scar ever gets irritated or red or somethin', some reason, I just get off it for a day, right? Yeah, you have to be vigilant.

**Vigilance in urinary tract care.** Vigilance in preventing bladder or urinary tract complications was a recurring theme among the participants. Most commonly, this was indicated by strategies to prevent urinary tract infections. One participant summarized the need to be vigilant: “I think as you age with a spinal cord injury, your...bladder care require(s) more oversight.”

Seven participants reported that they had experienced little to no change in their bladder/urinary tract health as they transitioned through middle age. Four of these participants credited their vigilance in bladder care for keeping them free from complications, as reflected in this statement:

I have seen very little change with my bladder over the years even though I have had my share of bladder infections. I think this is because I am extremely careful with my bladder care – not letting my bladder get too full and making sure that I keep myself well hydrated.

Another participant described his bladder function as improved in his middle age years. He related this to his vigilance in caring for his bladder health:

I take cranberry tablets twice a day, plus 2000mg of Vitamin C. At work I just pound water. And I cath myself like four, four times a day on average - four to five. I'm pretty strict about that at work...just pound water. Not thirsty, just drink it. And cath on a regular schedule...you know, I haven't had any urologic surgeries in a while...and I'm hoping I can keep that going.

This participant was one of six who specifically emphasized the importance of drinking water vigilantly to prevent bladder complications. As one participant emphasized, “Drink, drink, drink, drink, drink (water) and take care of those kidneys!”

**Vigilance in weight control.** The need for vigilance in weight control was discussed by 15 of the participants. Four of these participants reported no significant weight gain, and credited their personal vigilance for avoiding weight gain. As one of these participants stated:

I have not gained too much weight, but I think that is because I work very hard to keep my weight down. I know I need to work out, and do, regularly, to make sure that I do not put on any extra weight.

Another participant reported a significant weight gain that she had recently reversed through vigilant control of her diet and exercise.

Seven of the participants reported weight gain in their middle years, and they discussed the need for vigilance in exercising (n=5) and watching their diet (n=5) to control further gain and/or reduce their weight, while acknowledging the challenge of following through with their strategies. As one participant shared:

The weight's a little bit extra, too so... Been workin' at it, and sometimes it goes away and then it comes back. That's just a matter of actually making myself get religious about it and get out like I used to when I was younger, just do it every single day. Burn the calories and...I'm eating healthier, plenty of fiber, plenty of fresh fruits and vegetables; just sometimes it tastes good so you eat more!

Another participant who experienced weight gain reflected on the lack of anticipatory guidance that might have prompted her vigilance in weight control:

I think that if someone had said to me, you can minimize whatever might happen to you by staying very active, doing these things and keeping your weight down, I think as a younger person it would have been incorporated into my lifestyle. Now it's not. I'm just a slob. And I think that might, I don't know, I might've just sloughed off, but it always would have been in my head and maybe I would, I would've tried harder.

In general, the participants demonstrated vigilance in assessing or monitoring for potential changes, as well as in managing changes and preventing complications during their middle age years. Several participants described that aging brings about necessary changes, and that it is important to be vigilant and adjust to those changes. As one participant described:

Keep an open mind. I engage in as much exercise as possible, that has changed over the past ten or so years. Years ago I'd roll around the pond for a couple of miles, now I'm more inclined to do a passive swim with less wear on my upper extremity joints. Life changes so I change with it.

The importance of vigilance was acknowledged by all the participants, even those who did not necessarily consistently practice vigilance from the time of their initial injury. As one participant said, "I should have dealt more with the SCI as a chronic condition that needed constant monitoring/management. Maybe I could have avoided some of the subsequent injuries."

### **Figuring It Out**

In addition to *being vigilant*, another *strategy for living in uncharted territory* is *figuring it out*. As participants described various changes in physical function that they had experienced or were experiencing during their middle age years, they frequently shared their efforts to understand those changes, and perhaps to identify the causes for those changes. While *being vigilant* was likened to paying close, immediate attention to cues when travelling without a map, *figuring it out* has a more long-term perspective, which could be described as mapping one's own course. *Figuring it out* was evident in the reflections of 15 of the participants, which clearly demonstrated the interest of the participants in not only paying attention to their bodies on a day-to-day basis, but also understanding the trajectory of their changes in physical function. As one participant described, "I feel like Nancy Drew when I try to figure out what is happening with this body of mine." The need for the injured individuals to figure out why specific changes happen seems to flow in part from the fact that very little information is available to them, as another participant expressed:

We are really the ones who are the experts about this whole aging thing with a spinal cord injury... not many doctors really have that information, and I think people with spinal cord injuries really need to figure this all out as we live it.

For seven of the participants, *figuring it out* included the identification of other health issues, and determining if and how those issues interface with their SCI and the process of aging. As one participant stated, "We all have things after spinal cord injury that can come up 'cause they can come up in anybody." Several participants identified conditions that they stated were unrelated to their SCI, including COPD, the effects of Lyme disease, Parsonage-Turner Syndrome, eczema, arthritis, pneumonia, and menopause. Some participants were attempting to

attribute their changes in physical function to either the “normal” problems people experience or to aging with a SCI. For example, one participant responded to a question about skin changes:

I've got eczema... and again that probably just could happen to anyone, right, - you're aging... So that's a change, right... I don't know, that could happen to anyone I guess, right? It's not related to my spinal cord injury, I don't think.

Other participants seemed to relate their other conditions to their SCI condition. One example is an email participant who described the development of esophagitis as a result of treating a shoulder injury:

During this period of shoulder problems I took large doses of oral non-steroid anti-inflammatory medications. I developed a severe case of Gastroesophageal Reflux Disease. In 2008 I was diagnosed with Barrett's Esophagus. Not 100% sure but do believe that years of anti-inflammatory medicines contributed to the problems with my digestive system.

Several participants (n=5) described changes in physical function that were a result of what one participant referred to as “trade-offs.” One example of a trade-off is when a purposeful choice made by the individual to maintain health and/or independence has an anticipated negative impact on another aspect of physical function. For example, one participant talked about the fact that he prefers to sit up through the day, because this is best for his lungs. “But then,” he stated, “you can get more skin issues too!” This participant reported that he has in fact experienced a significant increase in “the battle with skin issues” during his middle age years, and attributed that change to the fact that he purposively chooses to stay up in his chair. Four other participants described situations in which their purposeful choices to remain active resulted

in pain and associated wear and tear injuries, but each of them described the trade-off as “worth it.” As one participant shared:

With age, and the wear and tear on my neck from painting, and typing with my mouth stick I’ve done a lot of damage to my neck. But it is worth it, because I really love the fact that I can paint and communicate. I’m willing to sacrifice to keep those things in my life.

Another participant shared an example of how trade-offs were worth it. She discussed her choice to use an indwelling catheter in spite of the fact that she figured out that her choice increased the occurrence of urinary tract infections:

My Urologist...wants me to self cath, I do not. Like I have mentioned, my fingertips are weak and I do not like the "rules" cathing every 4 hrs. no liquid after 6 p.m., cath in the middle of the night...no thanks, I have 3 hour meetings to sit through and not all bathrooms are "really" accessible, or clean. I do get occasional UTI but I can handle that.

For this participant, the freedom that she experienced from using an indwelling catheter was worth the trade-off of an increase in bladder infections. Each of these participants chose to live according to an identified value (i.e. being able to paint and communicate, and being able to participate in a three hour meeting without bladder issues) at the expense of something less valued or otherwise manageable (wear and tear injury to the neck, and occasional urinary tract infections).

For other participants, figuring out why they had experienced changes in physical function reflected a purposeful trade-off that did not work as anticipated. One participant described a loss of strength that occurred as she was intending to actually conserve energy:



It could be something that you do to save your energy, and before you know it, you're not able to do, you know, you saved your energy. You used the wheelchair to save your energy and a year down the road, you saved your energy too much, that when you try to do what you were doing before, you just don't have the muscle strength anymore.

Several participants went into great detail in trying to understand the complex interaction of factors that caused their changes in physical function. This complexity was poignantly illustrated in one participant's discussion about struggling to identify what caused her to stop walking during middle age after many years of being ambulatory post-injury:

I think it's amazing how I've seen the progression of me walking anywhere and everywhere, and then now I don't at all...In my early forties with injury, weight gain, changes in my muscles, um, and then being told, "Well, you can't expect to walk forever," and then the cellulitis, the breakdown of my, just skin changes, and uh, maybe it was because I never used the wheelchair, um, and then I did, I got a pressure sore on my buttock. Um, I never had any problems with pressure sores on my feet from the braces. And, I don't know what it was, but the calluses, they wouldn't, I don't know, the...the...I, the braces, um, it could have been weight gain - I don't know what caused it...

For some participants, the expressed motivation behind *figuring it out* was tied directly to finding a solution for an identified problem. One participant, who reported an increase in bladder spasms and UTI's in her middle age years, stated that "I cannot determine what causes them so I don't know how to get rid of them." Another participant stated, "I am trying to figure out why this pain has increased in the last few years. If I know what is causing the pain, maybe there will be something healthier that I can do about it."

*Figuring it out* and *being vigilant* are inter-related *strategies for living in uncharted territory*. When participants aging through their middle years with an incomplete SCI are attentive to their bodies (*being vigilant*), they often try to figure out what those changes are and why those changes are occurring. The result of *figuring it out* may well provide important knowledge that can motivate further vigilance.

### **Staying Positive**

Another subtheme of *strategies for living in uncharted territory* that arose from the participants' descriptions of their changes in physical function as they transition through middle age was the importance of *staying positive*. Ten of the participants specifically stated that keeping a positive attitude or positive outlook is a very important aspect of facing changes that arise. As one participant stated, "I think that if I did not have a positive attitude, the changes would sneak up on me much quicker, and I would not be working hard to keep my independence." Four of those participants acknowledged that keeping a positive attitude can be challenging, as worry and depression "creep in."

Participants offered some thoughts about how to maintain a positive attitude. Two participants specifically focused on helping others. "By helping others I find I focus less on my difficulties." Five other participants also emphasized the importance of "focus[ing] on what I can do rather than what I cannot." As another participant stated,

I think it is important to focus on your abilities not your disabilities. That doesn't mean putting your head in the sand and being unrealistic about things. But I think that too many people might let the fact that they have a SCI limit what they can do. I think that a can-do attitude has helped to keep me active and healthy. Having that positive attitude

really helped me when I was first injured, and I think that it is important to keep that positive attitude now as I face some new challenges that come with getting older.

One participant demonstrated a positive attitude in reframing or redefining a negative occurrence into a positive one.

The spasticity that I've had over the years, I've looked at as a positive...because it forces me to move. If I didn't have any spasticity, then I could be very sedate for several hours and have pressure sores...So anytime I'll have that spasticity I remember that there's a positive to that 'cause I know folks who have had their nerves cut, uh, persons with spinal cord injury, either paras or quads and have had their nerves cut so they don't have the spasticity which is great, at the same time it's not great because it doesn't force them to move around, uh, and, uh, and so spasticity is not a bad thing...spasticity can, can be a good thing.

Seven of the participants identified positive aspects associated with the fact that their injuries were incomplete rather than complete SCI's. Most commonly, they were positive about the fact that they had retained some sensation (n=5), which they identified as very beneficial for avoiding skin breakdown.

I'd rather be incomplete than complete because one of the things with a complete injury is if you're not feeling the pain, you may not feel the pressure. The pressure oftentimes indicates that there's an issue... I'd rather, I'd rather have that, the issue of the pain, not that I'm saying I like pain, - nobody does, but I'd rather have that issue and be aware of it then not be aware of it at all.

In contrast, one other participant spoke of the sensation in her legs in a negative light, saying that the pain and tingling she experiences are uncomfortable, and, her peers with complete SCI's do

not understand this discomfort, since they do not have the sensory function that she has with an incomplete injury.

Another participant offered a contrasting perspective to the theme of staying positive. She discussed that there can be so much emphasis on “what you have left” with an incomplete injury that individuals don’t focus appropriately on dealing with their losses or deficits. She reflected back on the time immediately after her injury, when there was “zero” emphasis on what changes in physical function might be forthcoming as she grew older.

All I got was, you’re so lucky to be alive. That was my whole thing, I never got a chance to grieve...I never really got a chance to grieve the loss of my senior year of college, you know, I had to go back and do it with the class behind me. Um, just my normalcy, you know, I never got a chance, it was always, you’re so, you’re so lucky, that you didn’t have a permanent injury and were a quadriplegic and didn’t die and, and so that was always the focus, not poor you, you had this terrible accident, no one ever said that.

### **Recognizing the Impact of Changes**

Another theme that arose in 13 of the participants’ descriptions of changes in physical function through their middle years was *recognizing the impact of changes*. Some participants commented that changes which might be considered part of “normal aging” for able-bodied people may have a much more significant impact on individuals living with SCI than on the general population. As one participant stated, “While many [middle-aged] able-bodied men experience similar physical changes to long term SCI men (weight gain, joint pain, fatigue, etc.), these don’t usually have as great an impact on independence and quality of life.” He went on to describe an example of the significant impact of a moderate weight gain, saying, “If my wife gains 10 pounds, she has to buy a new pair of pants. If I gain those same 10 pounds, I can no

longer transfer into my shower chair, and my independence is threatened.” Five other participants discussed that weight gain, even in what are “insignificant” amounts for able-bodied people, has a major impact on their functional abilities. As one of them said, “Even five pounds makes a difference with transfers.” This theme was evident in the comments of wheelchair users but also ambulatory individuals, one of whom stated, “a little bit of weight throws the balance off.”

Another factor related to the impact of weight gain that was discussed by several participants was the greater challenge to lose weight once it has been gained. Although most of the participants indicated that they exercise regularly, weight loss is particularly challenging for individuals aging with a SCI. As one non-ambulatory participant said, “the extra weight is extremely hard to get rid of, since upper body exercises are all I’ve got.” Participants who are ambulatory also indicated that they have difficulty with weight loss. As one stated, “The ways a person with an SCI can exercise are more limited...[and] a person with an SCI is going to have less stamina and thus exercising is more difficult.”

Several participants mentioned that increased fatigue is part of “normal” aging, but the impact of that fatigue is greater on someone with a SCI:

I have experienced normal aging like getting tired more easily. I finally went to a tilt system on my wheelchair to allow some resting during the day. I am certainly able to manage it, but getting older is a lot more complicated for someone like me. I can’t just take a break and put my feet up for a few minutes like an able bodied person.

A few participants described how their changes in physical function have a significant impact on their ability to be spontaneous. As one of them stated:

I spend quite a bit of time thinking about how I'm going to get from point A to point B in the most efficient way. That level of planning has definitely increased as I have gotten older, and I am experiencing more weakness. I find that my able-bodied peers are still much more likely to “get up and go” without thinking through things.

One participant offered another example of an age-related physical change that has greater impact on her because of her SCI:

My skin has gotten pretty dry as I have gotten older and my skin ended up cracking really badly on my left hand, and it hurts. If this happened to anyone without an injury, no big deal. But I need my hands to push my chair and transfer, and so this is a big pain in the neck for me.

Several other participants talked about the impact of any shoulder or arm injuries on an individual aging with a SCI. Referring to her arms, a participant stated, “I have to be so careful because these are my legs, you know, these are my legs and if I do anything to 'em, I'm in trouble.” These participants described the impact of a shoulder injury on transfer ability, the ability to move through their environment, and their general sense of independence.

There is a link between *recognizing the impact of changes* and the strategy of *being vigilant*. This link was identified by one of the participants during a member check, when she was first presented with the sub-theme of *being vigilant*:

I definitely think that people with incomplete spinal cord injuries have to be vigilant, because if anything starts to go wrong, it can very quickly have a huge difference for us. Like, if I do not pay close attention to a little twinge of pain in my shoulder, and if I don't rest that shoulder right away, I will end up with a problem that totally limits my mobility.

A normal person can function pretty well with a bum shoulder, but I am totally dependent on my shoulders to wheel and to transfer.

This participant described the fact that vigilance is required because of the significant impact of changes.

Three participants offered an interesting perspective on the impact of changes in physical function related to aging with an incomplete injury as compared to a neurologically complete injury. These participants expressed that with incomplete injuries, they actually had more to lose than individuals with complete injuries. As one of these participants said:

I guess in many ways I have yet to lose what a complete SCI has already lost. In other words, the process of aging in me may bring about more loss post injury than those with a complete SCI will experience post injury.

Another one of these participants likened the experience of aging with an incomplete SCI to post-polio syndrome, saying that “you ‘beat it’ once but then it’s back.” These three participants were among those that were ambulatory post-injury, and, in fact, continue to walk at the time of their interview.

Six participants described the impact of their changes in physical function on their families. Four of these were men, who expressed concern about the impact of their physical changes on their wives. One of them reflected on some increased weakness, and said, “I do find that I am reaching for my wife’s shoulder more frequently when we are walking, and I need to make sure that I am not hurting her back because I am not using another form of support.”

Another man stated that his recent 10 pound weight gain has affected his transfer ability, and said, “This puts a lot of pressure on my wife, who is always gracious about helping me, but I am

fearful about hurting her.” One of the women discussed the impact of her changes in physical function on her elderly mother:

My biggest concern with aging is that my Mom is my primary caregiver. She’s a robust 80 and still works as an RN full time, but obviously, this will change. As I get older and experience more changes, I feel like this adds a great deal of strain for my Mom.

Two of the participants stated that they are concerned that their changes in physical function as they age will have a burdensome effect on their children.

### **Summary**

In summary, the 17 participants provided a rich description of the changes in physical function experienced by individuals aging through middle age with a traumatic incomplete SCI. Participants described a variety of changes in different body systems, with the most common areas of change being decreased muscle strength, decreased endurance, weight gain, and wear and tear injuries. In terms of timing, the great majority of the identified changes were described as gradual.

The participants identified that they have received very little, if any, information about changes in physical function experienced through middle age. Their identified sources of information were limited and extremely diverse. Most of the participants indicated that they wanted more information to assist them through the middle age transition. From this data, the first of three themes arose: *travelling through uncharted territory*.

As participants described their experiences of transitioning through middle age without much anticipatory knowledge, the data revealed several *strategies for living in uncharted*



*territory*. Three sub-themes were *vigilance*, *figuring it out*, and *staying positive*. Vigilance was demonstrated by each participant, as each described personal strategies for monitoring and managing physical changes that come with middle age and for preventing possible complications. Participants also described their efforts to understand and identify the causes for changes in physical function; in other words, to *figure it out*. The participants emphasized the importance of *staying positive* as another essential *strategy for living in uncharted territory*. Ten of the participants specifically stated that keeping a positive attitude or positive outlook is very important when facing unanticipated changes in physical function. Finally, the experience of these participants revealed the theme of *recognizing the impact of changes*.

## Chapter 5

### Discussion

The purpose of this QD study was to describe the changes in physical function experienced by participants aging through middle age with a traumatic incomplete spinal cord injury from their own perspective. Seventeen participants provided a rich description of this transition, which revealed three themes: *travelling through uncharted territory*, *strategies for living in uncharted territory* (with the sub-themes *being vigilant*, *figuring it out*, and *staying positive*), and *recognizing the impact of changes*. In this chapter, each of these themes is discussed, as well as the predominant changes in physical function described by the participants. Comparisons are made to the unfolding literature base on aging with an incomplete SCI. Implications for nursing and health care practice, as well as recommendations for future research with this population, are summarized and study limitations are presented.

### **Theoretical Underpinnings**

The theoretical framework which undergirded this study was the transitions theory conceptualized by Meleis et al. (2000). This middle-range theory provided a broad framework for exploring the changes in physical function experienced by individuals as they transition through middle age, which involves a developmental transition and a simultaneous health and illness transition, as they live with the chronic effects of an incomplete SCI. Transition theory shaped the research questions and the development of the interview guide, and provided a framework for data analysis. The data reflect several transition properties in participant experience, including specific *changes and differences*, the *transition time span*, and to some extent, *critical points* of time related to those changes. One transition property dominant in the participants' descriptions was *engagement*, which is demonstrated by active participation by an

individual in facing challenges and altering activities. The transition condition of *preparation and knowledge* undergirded insights gleaned in the data analysis regarding the lack of accessible anticipatory knowledge described by participants. Thus, transitions theory provided a good background for exploring the participants' descriptions of their changes in physical function through middle age. The study findings suggest that ongoing research may fit more closely with the concept of self-management, which is a predominant theme across the healthcare literature as the number of individuals living with chronic illness and disabilities has increased exponentially (Richard & Shea, 2011; Schulman-Green et al., 2012; Udliis, 2011). The potential alignment with self-management is apparent in the discussion below.

### **Travelling through Uncharted Territory**

The lack of anticipatory knowledge described by study participants is likely due, at least in part, to the lack of research about the experience of aging with any SCI. Participant experience reflects the conclusions of the integrative review completed prior to initiation of this study, and reports published during data collection and analysis (Groah et al, 2012; Heinemann, Steeves, Boninger, Groah & Sherwood, 2012; Krause & Bozard, 2012; Sakakibara, Hitzig, Miller, & Eng, 2012; Werhagen, Aito, Tucci, Strayer & Hultling, 2012).

Although the research base about aging with a SCI is growing, this study identified a lack of accessible knowledge for the injured participants themselves. The finding that participants identified the internet as the most common source of information about aging with a SCI, is consistent with the current research literature that reports a relatively high use of the internet as a health information source for individuals living with SCI (Burkell, Wolfe, Potter & Jutai, 2006; Goodman, Jette, Houlihan & Williams, 2008; Jetha, Faulkner, Gorczynski, Arbour-Nicitopoulos & Martin Ginis, 2011; Libin et al., 2011).

Perhaps the most important finding relative to anticipatory knowledge was the perceived lack of information from health care providers. The fact that some participants emphasized that they often needed to educate their physicians about SCI is reflective of the literature, which indicates that many primary care providers are unfamiliar with the needs of individuals aging with a SCI (Donnelly et al., 2007; Groah et al., 2012). The findings in this study are also consistent with a recently published study from Norway, which found that individuals with SCI reported a low level of satisfaction with their general practitioners' knowledge about SCI (Hagen, Grimstad, Bovim & Gronning, 2012). Hagen et al. found the lowest level of satisfaction in patients with incomplete injuries. Although the study was not specific to aging with a long-term SCI, the researchers reported that individuals in the 35 to 49-year-old range were the least satisfied with their general practitioner.

The theme of travelling through uncharted territory initially seems to be related to the concept of uncertainty, as this theme clearly suggests that participants are facing the unknown, a prime attribute of uncertainty (Penrod, 2007). However, further reflection on the concept of uncertainty shows the findings from this study do not align closely with uncertainty. In particular, the concept of uncertainty is characterized by feelings of discomfort and uneasiness (Elphee, 2008; Penrod, 2007), which were not commonly reflected in the participants' descriptions of their experiences. Instead, participants focused on describing three strategies for living in uncharted territory.

### **Strategies for Living in Uncharted Territory**

The finding that study participants have not received much guidance from external sources may be linked to the finding that these participants often describe taking personal responsibility for managing changes themselves, using the three strategies of *being vigilant*,

*figuring it out*, and *staying positive*. These three strategies are somewhat reflective of the concept of self-management. Aging with an incomplete SCI has not yet been examined from a self-management perspective, but several themes that arose in this study suggest that the concept of self-management may provide a suitable framework for future research.

### **Being Vigilant**

Being vigilant appears to be linked to the concept of self-management. For example, a recent concept analysis on self-management in chronic illness identified *active participation* as an essential dimension of self-management (Udlis, 2011). The vigilance described by participants in the current study reflects their active participation in managing their changes in physical function. A recently published meta-synthesis reviewed self-management processes in chronic illness, and identified a number of these processes that reflect the theme of *being vigilant*, including “monitoring and managing symptoms...and body responses... modifying diet, nutrition...and physical activity...[and] taking action to prevent complications” (Schulman-Green et al., 2012, p.139). These research publications were clearly focused on self-management in chronic disease or chronic illness, and appear to be reflective of the experience of aging with a long-term SCI. However, there is a clear call to examine self-management strategies among individuals aging with SCI, both from this current study and the recent literature.

A consortium of expert researchers examining aging with SCI recently published a State of the Science paper enumerating a number of recommendations for research (Heinemann et al., 2012). Among their recommendations, they highlighted the priority for research on self-management of health conditions within the SCI population. Another group of renowned SCI researchers recently published an analysis of the state of the science in SCI and aging (Groah et al., 2012). They listed several priority areas where new knowledge is needed. One of their

priorities was to explore: “What are the most effective strategies for helping individuals with SCI prevent or delay the onset of health conditions associated with aging?” (Groah et al., 2012, p.87). Another unanswered question they posed was: “What are the most effective strategies for decreasing the negative impact of aging-related health conditions that emerge on physical functioning...?” (Groah et al., 2012, p.87).

This study provides a foundation for exploring self-management strategies specifically utilized by individuals with incomplete SCI, an experience that shares some characteristics with the general SCI population, and diverges in other areas. For example, one unique aspect of aging with an incomplete SCI versus a complete injury is being vigilant to attend to sensory cues below that level of injury. The strategy of *being vigilant* described by participants in this study should be explored within the context of a self-management model.

### **Figuring it Out**

Like *being vigilant*, the strategy *figuring it out* appears to be related to the concept of self-management, which involves learning and gaining knowledge through personal experience (Schulman-Green et al., 2012; Udalis, 2011). Determining what is happening and why those changes are occurring provides a strong basis for intervention, either in employing preventative measures or in mitigating negative changes.

Another part of *figuring it out* described by participants was exploring how aging with an incomplete SCI might interface with other aspects of health, for example, acute illnesses or genetically-based cardiovascular changes. A widely suggested priority in future research on SCI and aging is to explore the interaction of SCI and other age-related health conditions (Groah et al., 2012; Heinemann et al., 2012; Hitzig, Eng, Miller, & Sakakibara, 2011; Jensen et al., 2012). This study highlights the potential value of involving individuals aging with an incomplete SCI,

as they can provide an emic perspective about how different illnesses and secondary health conditions interface with their incomplete SCI.

One aspect of *figuring it out* that participants identified was making conscious trade-offs, when a purposeful choice made by the individual to maintain health and/or independence has an anticipated negative impact on another aspect of physical function. Individuals aging with an incomplete SCI and their health care providers would benefit from research that would help guide these choices. For example, one participant described the choice to conserve his energy and avoid shoulder wear and tear by using a power wheelchair rather than a manual wheelchair. The literature on aging with an SCI typically advocates the avoidance of activities that stress the shoulders in order to avoid long-term shoulder damage, supporting the strategy of purposeful trade-offs. However, one recent review article questions the conventional wisdom, and proposes that avoiding shoulder overuse may actually be contributing to de-conditioning and ultimately causing more injuries (Chiodo, 2010). This proposition is reflective of the unexpected consequences of trade-offs that some participants described in this study.

### **Staying Positive**

The final strategy for living in uncharted territory that was described by a majority of the participants was *staying positive*. In contrast to the “discomforting, uneasy sensation” typically associated with uncertainty (Penrod, 2007), this study found that participants highly valued their positive attitude, describing that attitude as a motivator for *being vigilant* and *figuring it out*. They described their choice to focus on their abilities rather than their disabilities as they utilize strategies to face changes in physical function as they age. This attitude is reflected in a recent study by Krause and Bozard (2012, p. 229), who conducted a 35-year longitudinal study of life changes after SCI:

There is always the temptation to view the course of SCI as a negative process associated only with declines, but life appears to evolve with aging after SCI, as those who survive rely on their ability to adjust and adapt to the changing circumstances.

The findings from the current study provide a foundation for exploring the importance of a positive outlook for individuals aging successfully with a long-term SCI. A self-management perspective would again provide a strong basis for this investigation, as this model identifies the skill of maintaining a positive outlook as a resource for effective self-management (Schulman-Green et al., 2012), and proposes that depression decreases self-management capability (Grey, Knafl, & McCorkle, 2006).

Several participants described their positive outlook by focusing on the advantages of having an incomplete SCI rather than a complete injury. This is consistent with the concept of social comparison, for example, contrasting oneself with those who are “worse off.” This concept has recently been studied in relationship to quality of life in individuals with SCI (vanLeeuwen, Kraaijeveld, Lindeman & Post, 2012), but has not yet been examined specifically in the population of those aging with a long-term incomplete SCI (Sakakibara et al., 2012).

### **Recognizing the Impact of Changes**

The final theme identified in the participants’ descriptions of changes in physical function experienced through middle age was *recognizing the impact of changes*, as a majority of participants described greater impact due to changes in physical function than what their able-bodied counterparts might experience. This study found a link between this theme and the strategy of *being vigilant*. Perhaps fostering a clearer understanding of the potential impact of changes could motivate vigilance in assessing early changes or engaging in preventative measures to avoid changes. Further research is needed to understand more about the impact of



changes for people aging with incomplete SCI. Two recent studies which examined the impact of secondary complications in individuals with chronic SCI offer some tools for assessing the impact of changes from the perspective of the individual with a SCI. Kalpakjian, Seleza, Forchheimer, and Toussaint (2007) developed and tested the SCI Secondary Conditions Scale, and Hetz, Latimer, Arbour-Nicitopoulos, Ginis, and the SHAPE-SCI Research Group (2011) adapted this scale to create the Secondary Health Complications Survey. These tools list a variety changes or complications commonly experienced by individuals with SCI. Participants were asked to rate the impact of the change or complication on their daily life. The impact rating for the SHCS is a five-point scale, ranging from zero (no impact at all) to four (very severe impact). Neither of these studies focused on the changes specific to individuals with incomplete SCI, nor did they focus specifically on individuals in their middle age years. However, these studies provide a model for future research to further explore the impact of changes in physical function identified in this study.

Another potentially important finding arose from some of the participants' varied descriptions of recognizing the impact of change as it relates to incomplete injuries. This finding supports the literature-based supposition that individuals with an incomplete SCI comprise an heterogeneous population (DeVivo & Chen, 2011; Freixes, 2012), and provides yet another avenue for further research examining the unique experience of ambulatory individuals aging with SCI, a large subset of the population of individuals with incomplete SCI (Burns, Golding, Rolle, Graziani & Ditunno, 1997; Freixes, 2012).

### **Identified Areas of Physical Changes**

One of the specific aims of this research was to explore changes in physical function identified by participants with an incomplete SCI as they experienced aging through the middle

years. The participants described several common areas of change, which were almost exclusively described as gradual, often beginning around the age of 40. The identification of the types of age-related problems that are most likely to affect individuals with a SCI, and the timing of those changes, continues to be a high research priority (Groah et al., 2012; Hitzig et al., 2011; Jensen et al., 2012; Werhagen et al., 2012). The following sections detail the most commonly described changes in physical function, and compare the findings from this study to other research findings in the literature.

### **Decreased Muscle Strength**

The most common change described by participants was decreased muscle strength or increased weakness, which is consistent with the findings of an early study on aging with any SCI (Gerhart et al., 1993) and a more recent study that associated the need for more assistance with a loss of strength (Savic et al., 2010). This finding also supports non-research literature that identifies increased weakness as a particular problem occurring in those with incomplete SCI (Gerhart et al., 2000; Craig Hospital, n.d.).

Interestingly, none of the participants discussed the concept of *being vigilant* in an attempt to prevent or mitigate this decrease in strength. Perhaps this is because it is commonly understood that normal aging is often characterized by decreased muscle strength. However, cellular and system-level muscle changes have a much more profound impact on individuals aging with a SCI (Chiodo, 2010), which may herald the need for more vigilance. Decreased muscle strength was part of *figuring it out* for several participants, as they attempted to understand how and why certain changes in physical function had occurred. In a future study, it would be interesting to explore what physical changes over which the participants sense some degree of control, and what changes are perceived as beyond their control. Within a self-

management framework, individuals are more effective in their ability to self-manage a chronic condition when they demonstrate confidence and self-efficacy (Grey, Knafl & McCorkle, 2006; Schulman-Green et al., 2012).

### **Weight Gain**

Many of the participants identified weight gain as a significant change they experienced through their middle age years, consistent with the current literature indicating that approximately three-fourths of the chronic SCI population is overweight or obese (Groah et al., 2012; Groah et al., 2011; Laughton, Buchholz, Martin Ginis, & Goy, 2009), and there is a growing body of literature about cardiovascular risk factors in individuals aging with any SCI, including overweight and obesity (Bauman & Spungen, 2008; Buchholz & Bugaresti, 2005; Groah et al., 2011; Hetz et al., 2011; Hitzig et al., 2011). A recent pilot study (Crane, Little & Burns, 2011) explored weight gain in the first five years after SCI; however, no studies were found that examined weight gain as individuals aged through their middle years. There is a clear need for ongoing research about weight gain when aging with a SCI, including the development of effective strategies to prevent weight gain in this population (Jetha et al., 2011; Kehn & Kroll, 2009).

### **Decreased Endurance**

Over half of the participants described a decrease in endurance in their middle age years. The term endurance is rarely used in the SCI research literature, but is perhaps best inversely related to fatigue, which has been found to increase significantly in individuals as they age with an incomplete SCI (Fawkes-Kirby et al., 2007). A subsequent study examined the occurrence of fatigue in ambulatory individuals with incomplete SCI, which suggested that fatigue is a significant problem for this population (Freixes et al., 2012). This addition to the literature is

encouraging because of its specific focus on individuals with incomplete injuries (specifically ASIA D ambulatory subjects); however, this study only included subjects who had a DOI of one to eight years, and no current studies were found which explored fatigue or decreased endurance in middle age.

### **Wear and Tear Injuries**

Participants also described different wear and tear injuries that they have experienced during middle age, most commonly in their shoulders a finding that is consistent with a significant amount of research evidence detailing the increase in shoulder injuries in individuals with SCI secondary to long-term wheelchair use and transfers using the upper body (Brose et al., 2008; Hetz et al., 2011; Hitzig et al., 2011; Jensen, Hoffman & Cardenas, 2005; Kivimaki & Ahoniemi, 2008). No literature was found addressing wear and tear injuries in ambulatory individuals aging with a SCI, highlighting another knowledge gap in regards to individuals with less severe (ASIA D) SCI.

### **Bladder**

Half of the eight participants who reported changes in their urinary tract health described changes in bladder management methods, which is consistent with the findings in a recent longitudinal study that found the use of suprapubic catheters increased with age in a sample that included individuals with incomplete as well as others with complete SCI (Savic et al., 2010). Only three participants reported an increase in UTI's during their middle years. In their recent longitudinal study, Savic et al. (2010) reported a significant decrease in the occurrence of UTI's, but found UTI's were still the most frequently reported medical problem for individuals aging with a long-term SCI. Although an increase in UTI's was not described by many participants in the current study, the occurrence of UTIs in this population still warrants further attention, as

septicemia continues as a leading cause of death in individuals aging with a SCI (Strauss, DeVivo, Paculdo & Shavelle, 2006), and this septicemia is often attributed to recurrent infections related to urinary catheterization (Groah et al., 2012).

## **Bowel**

Some participants reported changes in bowel function, all of them reporting an increase in constipation. This finding may be low in comparison to findings reported in the literature. An earlier study found a significant increase in the occurrence of constipation for every decade post-SCI, regardless of completeness of injury (Menter et al., 1997). More recent research literature on bowel changes in individuals aging with SCI also indicates an increase in constipation-related symptoms with increased DOI (Faaborg, Christensen, Finnerup, Laurberg & Krogh, 2008; Hitzig et al., 2011). However, the participants in this study described specific self-management strategies they employ for avoiding bowel issues, such as vigilant attention to the effect of their diet on bowel function, which may explain why the perception of change was relatively low. This is consistent with a recent study that reported the effective use of a combination of medications, dietary practices, and other bowel stimulation methods to improve bowel function (Savic et al., 2010).

## **Timing of Changes in Physical Function**

An important aspect of understanding changes in physical function is to reflect on the timing of those changes. Participants in this study described changes that were primarily gradual, most commonly beginning in their early forties. This finding seems consistent with the literature that proposes the occurrence of premature aging changes in individuals with SCI (Groah et al., 2012; Groah & Kehn, 2010; Hitzig et al., 2011); however, there is a need for more

research to confirm SCI as a model for early or accelerated aging (DeVivo & Chen, 2011; Groah et al., 2012; Heinemann et al., 2012; Hitzig et al., 2011; Jensen et al. 2011).

### **Reflections on Recruitment and Sampling**

Recruitment of the study sample of 17 participants proved to be extremely challenging. In this section, the various recruitment strategies are reviewed in light of their effectiveness, and recommendations for gaining a sample for future research endeavors with this population are proposed.

#### **Effective Recruitment Strategies**

Recruitment for this study was greatly dependent upon the assistance of the NERSCIC and the GBC of the NSCIA in facilitating communication via their email contact lists, which the staff graciously offered in support of this student's work. Interestingly, all of the participants who responded as a result of the GBC communication reside outside of New England. This seems to indicate that email and internet communications for this local agency reaches beyond their geographic target audience. For future research in this field, other regional chapters of the NSCIA as well as other SCI associations could be utilized.

The GBC email also indirectly provided two additional participants through snowball sampling. The two participants gained through snowball sampling proved to be very valuable in reaching data saturation at a time when other recruitment strategies were no longer yielding additional participants. The number of inquiries from potential participants resulting from this strategy indicates that snowball sampling is an effective addition to other sampling strategies, and should be utilized in future research with this population.

#### **Future Potential Recruitment Strategies**

In this study, professional networking yielded only one participant. In future research projects, it may be worth pursuing participants through urology practices. Most of the participants in this study described complex bladder management processes that require oversight by an urologist. Urologists were the most frequently mentioned category of medical specialty in the interviews. In retrospect, more vigorous pursuit of potential participants through urology practices may have been helpful in the challenging task of recruitment.

One subset of the SCI population that was not represented in this study was individuals with a military background who receive their care through the Veterans Administration (VA) healthcare system. Recruiting military veterans through the VA hospitals or clinics for participation proved to be unfeasible for this study. In future research about aging with an incomplete spinal cord injury, the investigator could attempt to partner with a VA-affiliated researcher, or recruit through community-based programs where veterans gather.

### **Implications for Practice**

Nurses and other health care providers are well-positioned to be a valuable source of information for individuals aging with an incomplete SCI. This information should be part of routine patient education for any individual with an incomplete SCI, beginning in the acute rehabilitation setting and continuing through the ongoing care of individuals living with an incomplete SCI (Groah & Kehn, 2010; Thietje et al., 2011), providing guidance to individuals and their families. As it becomes available, information about anticipated changes in physical function with aging must be disseminated to individuals with SCI, as information is an essential antecedent to effective self-management (Schulman-Green et al., 2012; Udulis, 2011). Web-based information sources also provide an accessible forum for knowledge dissemination, and

the findings of this study indicate the need to direct individuals aging with incomplete SCI to appropriate on-line knowledge resources.

A group of Swiss researchers recently developed a computerized tool to support the long-term “follow-up care process in people with spinal cord injury in daily clinical practice” (Spreyermann et al., 2011, p. 230). This tool was designed to facilitate ongoing assessment and care of individuals aging with a SCI by an interdisciplinary healthcare team. The visual report that is generated with this tool is intended to be shared with the patient, and “serve[s] as a basis for discussion about the patient’s priorities, dispositions, and long-term goals, thus providing an optimized and individual health-coaching session...help[ing] to involve the individual with SCI fully as a partner” (Spreyermann et al., 2011, p. 231). Review of this tool and subsequent evaluation of its implementation in Switzerland and in other countries may be a first step toward providing a useful instrument to facilitate communication between health care providers and individuals with incomplete SCI.

### **Implications for Health Care Education**

Clinician education is imperative, and requires purposeful, effective strategies for incorporating new knowledge into basic and continuing education programs for nurses, physicians, and other health care providers caring for individuals aging with an incomplete SCI (Groah & Kehn, 2010; Kehn & Kroll, 2009). Findings from various research studies should be reported in practice-oriented publications and websites, and incorporated into continuing education opportunities for providers currently caring for individuals with incomplete SCI, either in rehabilitation settings or in primary care settings. Academic programs in nursing and other health care professions should consider including didactic content and clinical experiences that



include a long-term perspective of SCI as they prepare new practitioners to meet the needs of their patients.

### **Implications for Research**

This study suggests a need for further research to determine what strategies are effective in managing or preventing changes in physical function for individuals aging with an incomplete SCI. The study also provides some insight from the perspective of individuals with incomplete SCI about strategies they employ as they transition through middle age, and contributes to this identified knowledge gap. Further research is warranted to examine the effectiveness of those strategies. Based upon the findings from this study, a self-management framework appears to provide an appropriate foundation for ongoing research. While many studies can include and benefit individuals aging with any SCI, future study designs should permit some exclusive focus on individuals with incomplete injuries, so that findings enable knowledge development about the unique experience of people with incomplete SCI.

One opportunity for future research based on the description from this study would be to conduct a quantitative study using a modified Secondary Health Complications Survey to explore the prevalence of the identified changes in physical function as well as the perceived impact of those changes. Statistical analysis of the responses could also reveal potential relationships between different changes in physical function. For example, Hetz et al. (2011) found that participants who identified themselves as overweight were more likely to report fatigue, pain, and overuse injuries, and rated the impact of these complications as higher than participants who did not identify themselves as overweight. This information could support subsequent intervention research, testing strategies that can help these individuals with an incomplete SCI, their families and their healthcare providers collaborate to prevent some loss of

function and plan for unavoidable changes associated with the transition of aging. More knowledge in this area could also contribute to the larger body of knowledge regarding self-management in multiple chronic disabilities and illnesses.

In spite of the fact that only a few participants have gotten information from peers, a number of participants expressed their willingness to share their experiences, along with other information about aging with an incomplete SCI, with other individuals with more recent injuries. Several participants recommended that results from this study could be used to write a guide that would be part of a peer-counseling program for newly injured individuals. Additionally, there is a need for research to assess the value of peer-to-peer information sharing between individuals with SCI (Boschen, Tonach & Gargaro, 2003; Groah & Kehn, 2010).

Another finding that provides an opportunity for future research is the concern described by participants about the impact of changes in their physical function on their family members or caregivers. This concern for the impact of changes on others may promote vigilance, which could help individuals aging with an incomplete SCI to avoid or mitigate harmful changes. Nurse researchers functioning within a holistic paradigm are well-positioned to explore the multi-faceted impact of changes beyond the individuals to their families. In addition, this theme heralds the need for new research to explore the experience of being a caregiver or a family member of an individual aging with a SCI. Groah et al. (2012, p.88) have highlighted the need for new knowledge to “examine caregivers who are aging and the effects on assisting the individual with SCI to maximize independence and functioning in the face of an increasing risk of chronic or acute health conditions.”

While they had some distinct differences, both interview methods were effective in gleaning descriptive data from the participants, and both should be employed in future research

with this population. A possible strategy for future research would be to employ telephone interviews. Another option would be to offer a Voice-over-Internet Protocol with video (such as Skype<sup>®</sup>) as a means of conducting interviews at a distance. Skype and other similar internet technologies have recently been proposed as a qualitative research interview medium, as it allows for synchronous interaction much like a telephone, but allows for visual interaction (Hanna, 2012).

### **Implications for Health Policy**

Knowledge gained from studies examining the long-term effects of living with a SCI, including the growing understanding of secondary health conditions, also has policy implications within the healthcare delivery system. First, continued funding of research in this area is imperative. Funding for aging with SCI research has been challenging, contributing to the ongoing knowledge gap (Groah et al., 2012). Secondly, health care reform is necessary to assure adequate access to preventative care and care related to secondary conditions or age-related changes, care which may not be required until many years after the original SCI (Groah & Kehn, 2010; Kehn & Kroll, 2009; Saunders, Krause & Selassie, 2010). One essential element of providing access to care is to promote policy changes by Medicaid and other insurers (Chiodo, 2010; Saunders, Krause & Selassie, 2010) based upon a growing understanding of the experience of aging with a SCI. Linking the experience of aging with a SCI to a chronic illness focus could be beneficial, as chronic illness is a current National Institutes of Health priority for health services research and funding (U.S. Department of Health & Human Services, 2012).

### **Summary of Recommendations**

Based upon the findings of this study, priority recommendations for the next five years include the following:

- Researchers should conduct studies of effective self management strategies employed by people middle- aging with traumatic incomplete SCI.
- Researchers should explore effective mechanisms to disseminate new knowledge about effective self management strategies to people with SCI, their caregivers and families.
- Practitioners should engage their clients in an ongoing dialogue about their experiences of aging with an incomplete SCI until this knowledge gap is minimized.

### **Study Limitations**

Participant recruitment was challenging, which did not provide any opportunity for theoretical sampling, as each qualified individual was enrolled if they were willing to participate. Recruitment of participants for research on aging with a SCI has been clearly identified as a major challenge (Heinemann et al. 2012; Krause & Bozard, 2012), and this limitation should be anticipated in future research projects.

The study sample was comprised of all white or Caucasian participants, most of whom were well-educated and employed at least part time, which may not be reflective of the general population of middle-age individuals with incomplete SCI. One group that was not represented in this study was military veterans, although recent statistics estimate that one in five individuals living in the US with a SCI are veterans (Curtin, Suarez, DiPonio, & Frayne, 2012).

Individuals who respond to an invitation to participate in research may tend to exhibit characteristics that would accentuate certain themes. For example, individuals interested in participating in this type of research might be more vigilant, more interested in trying to figure out their changes in physical function, and they might tend to have a more positive outlook than other individuals who did not chose to participate.

Due to the small sample size, and the nature of qualitative research, generalizability to the larger population of individuals aging with an incomplete SCI is limited (Lincoln & Guba, 1985). Generalizability is also limited due to a dependence upon self-reports of diagnosis and duration of injury. Many participants were not aware of the ASIA classification of their injury, and individuals with older injuries may not have been classified according to the current standards (Hitzig et al., 2008), and therefore participants were included based upon their self-described SCI status as “incomplete.”

Another possible limitation was the risk of social desirability bias. This was projected to be more likely to be a factor with face-to-face interviews. A cited advantage of email interviews is the provision of some level of anonymity, which may limit the occurrence of social desirability bias (Beck, 2005; Holmes, 2009).

The use of a cross-sectional design is another study limitation. The most accurate research design to examine changes associated with aging is longitudinal, which examines subjects over time (Austad, 2001; Coll, 2007; DeVivo, 2004; Heinemann et al., 2012; Hitzig et al., 2011; Krause & Coker, 2006; Savic et al., 2010; Timiras, 2007; Werhagen et al., 2012). Because the purpose of this study was to describe changes in physical function from the perspective of the injured individual, data collection within a single time span is an appropriate method. However, responses of the participants were potentially subject to recall bias of subtle events.

### **Summary**

This is the first study to describe the changes in physical function experienced by participants aging through middle age with a traumatic incomplete SCI from their own perspective. Participants described a variety of changes, some of which are consistent with the

growing literature base on aging with any SCI. This study supports the literature-based supposition that individuals with traumatic incomplete SCI comprise a unique and heterogeneous population, sharing some characteristics with persons with complete SCI and diverging in other areas (Freixes et al., 2012; Valles & Mearin, 2009). A recent analysis of the trends in injuries and aging with SCI proposes that the percentage of incomplete SCI's is increasing (DeVivo, 2012), and there is a clear call for both quantitative and qualitative research methods to be employed to continue to build a strong knowledge base about these changes in physical function (Heinemann et al., 2012).

In this study, participants reflected on the lack of available information that they have about aging with an incomplete SCI, likening their experience *to travelling through uncharted territory*. They described *strategies for living in uncharted territory* that help them to prevent or manage changes in physical function, including *being vigilant* about watching for changes and responding to changes, investing time in *figuring out* what changes they experienced and why those changes happened, and staying positive. They also described the importance of *recognizing the impact of changes*. The findings from this descriptive study provide a foundation for further understanding of this transition. As part of a growing body of research, this study suggests clear foci for further research to support effective self-management and timely interventions for individuals aging with an incomplete SCI, which can ultimately promote wellness and improved quality of life (Grey et al., 2006; Krause & Bozard, 2012; Udalis, 2011) in this population.

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# Appendix A

## Standard Neurological Classification of Spinal Cord Injury

Patient Name \_\_\_\_\_

Examiner Name \_\_\_\_\_ Date/Time of Exam \_\_\_\_\_



### STANDARD NEUROLOGICAL CLASSIFICATION OF SPINAL CORD INJURY



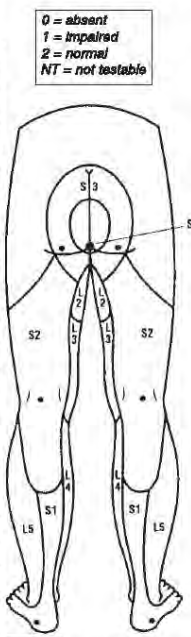
**MOTOR**  
KEY MUSCLES  
*(scoring on reverse side)*

	R	L	
C5	<input type="checkbox"/>	<input type="checkbox"/>	Elbow flexors
C6	<input type="checkbox"/>	<input type="checkbox"/>	Wrist extensors
C7	<input type="checkbox"/>	<input type="checkbox"/>	Elbow extensors
C8	<input type="checkbox"/>	<input type="checkbox"/>	Finger flexors (distal phalanx of middle finger)
T1	<input type="checkbox"/>	<input type="checkbox"/>	Finger abductors (little finger)
<b>UPPER LIMB TOTAL (MAXIMUM)</b>			
	<input type="checkbox"/>	+	<input type="checkbox"/> = <input type="checkbox"/> (50)

Comments:

L2	<input type="checkbox"/>	<input type="checkbox"/>	Hip flexors
L3	<input type="checkbox"/>	<input type="checkbox"/>	Knee extensors
L4	<input type="checkbox"/>	<input type="checkbox"/>	Ankle dorsiflexors
L5	<input type="checkbox"/>	<input type="checkbox"/>	Long toe extensors
S1	<input type="checkbox"/>	<input type="checkbox"/>	Ankle plantar flexors
<b>LOWER LIMB TOTAL (MAXIMUM)</b>			
	<input type="checkbox"/>	+	<input type="checkbox"/> = <input type="checkbox"/> (50)

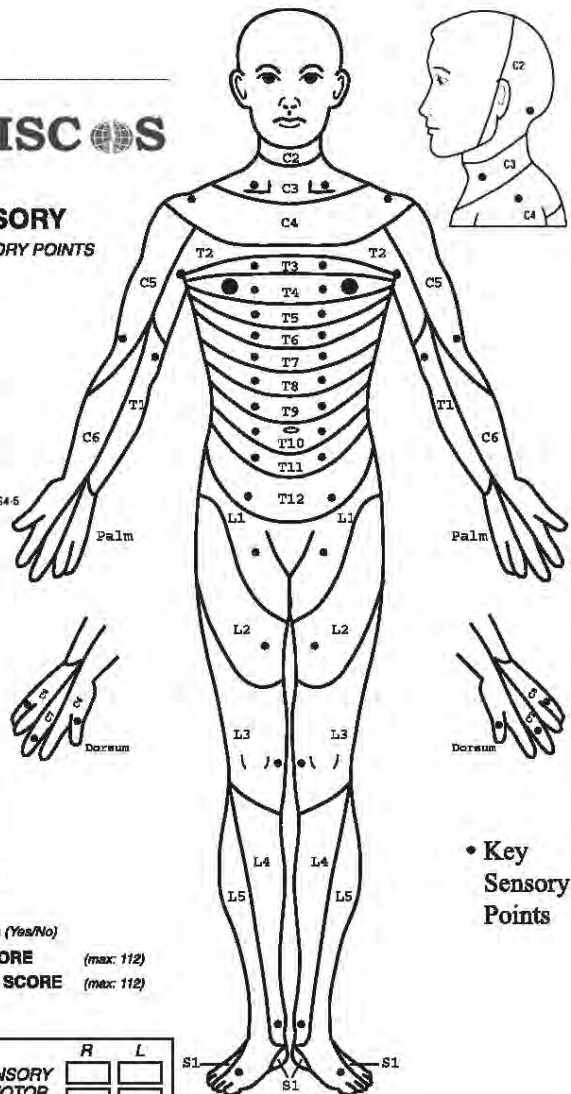
	LIGHT TOUCH		PIN PRICK	
	R	L	R	L
C2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C6	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C7	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C8	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T6	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T7	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T8	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T9	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T10	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T11	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T12	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
S1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
S2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
S3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
S4-5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>TOTALS</b>				
	<input type="checkbox"/>	+	<input type="checkbox"/> = <input type="checkbox"/> (50)	<input type="checkbox"/>



0 = absent  
1 = impaired  
2 = normal  
NT = not testable

Any anal sensation (Yes/No)   
**PIN PRICK SCORE** (max: 112)  
**LIGHT TOUCH SCORE** (max: 112)

**SENSORY**  
KEY SENSORY POINTS



• Key Sensory Points

<b>NEUROLOGICAL LEVEL</b> <small>The most caudal segment with normal function</small>	SENSORY	R	L	<b>COMPLETE OR INCOMPLETE?</b> <small>Incomplete = Any sensory or motor function in S4-S5</small>	<input type="checkbox"/>	<b>ZONE OF PARTIAL PRESERVATION</b> <small>Caudal extent of partially innervated segments</small>	SENSORY	R	L
	MOTOR	<input type="checkbox"/>	<input type="checkbox"/>				MOTOR	<input type="checkbox"/>	<input type="checkbox"/>
<b>ASIA IMPAIRMENT SCALE</b>					<input type="checkbox"/>				

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REV 03/06

## MUSCLE GRADING

- 0 total paralysis
- 1 palpable or visible contraction
- 2 active movement, full range of motion, gravity eliminated
- 3 active movement, full range of motion, against gravity
- 4 active movement, full range of motion, against gravity and provides some resistance
- 5 active movement, full range of motion, against gravity and provides normal resistance
- 5\* muscle able to exert, in examiner's judgement, sufficient resistance to be considered normal if identifiable inhibiting factors were not present

NT not testable. Patient unable to reliably exert effort or muscle unavailable for testing due to factors such as immobilization, pain on effort or contracture.

## ASIA IMPAIRMENT SCALE

- A = Complete:** No motor or sensory function is preserved in the sacral segments S4-S5.
- B = Incomplete:** Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5.
- C = Incomplete:** Motor function is preserved below the neurological level, and more than half of key muscles below the neurological level have a muscle grade less than 3.
- D = Incomplete:** Motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade of 3 or more.
- E = Normal:** Motor and sensory function are normal.

## CLINICAL SYNDROMES (OPTIONAL)

- Central Cord
- Brown-Sequard
- Anterior Cord
- Conus Medullaris
- Cauda Equina

## STEPS IN CLASSIFICATION

The following order is recommended in determining the classification of individuals with SCI.

1. Determine sensory levels for right and left sides.
2. Determine motor levels for right and left sides.  
*Note: in regions where there is no myotome to test, the motor level is presumed to be the same as the sensory level.*
3. Determine the single neurological level.  
*This is the lowest segment where motor and sensory function is normal on both sides, and is the most cephalad of the sensory and motor levels determined in steps 1 and 2.*
4. Determine whether the injury is Complete or Incomplete (sacral sparing).  
*If voluntary anal contraction = No AND all S4-5 sensory scores = 0 AND any anal sensation = No, then injury is COMPLETE. Otherwise injury is incomplete.*

5. Determine ASIA Impairment Scale (AIS) Grade:

Is injury **Complete**? If YES, AIS=A Record ZPP  
(For ZPP record lowest dermatome or myotome on each side with some (non-zero score) preservation)

NO ↓

Is injury **motor incomplete**? If NO, AIS=B  
(Yes=voluntary anal contraction OR motor function more than three levels below the motor level on a given side.)

YES ↓

Are **at least half of the key muscles below the (single) neurological level graded 3 or better?**

NO ↓  
AIS=C

YES ↓  
AIS=D

If sensation and motor function is normal in all segments, AIS=E  
*Note: AIS E is used in follow up testing when an individual with a documented SCI has recovered normal function. If at initial testing no deficits are found, the individual is neurologically intact; the ASIA Impairment Scale does not apply.*

From: [http://www.asia-spinalinjury.org/publications/2006\\_Classif\\_worksheet.pdf](http://www.asia-spinalinjury.org/publications/2006_Classif_worksheet.pdf)



## Appendix B

### Empirical Research Matrix: Physical Changes in Individuals Aging with Spinal Cord Injury

Author	Sample Characteristics		Purpose	Research Design	Results
(Year)	Total n	Duration of injury (DOI) (in years)			
Country	# incomplete				
Fawkes-Kirby, Wheeler, Anton, Miller, Townson, and Weeks  (2007)  CANADA	n = 76  Inc. = 42	0.8 - 40  $\xi = 12.7$  23 > 20 yr DOI	To determine the prevalence of fatigue in an outpatient SCI population and examine the clinical variables contributing to that fatigue.	Retrospective chart review	57% of the sample were found to have fatigue severe enough to interfere with daily function.  Incomplete injury was a significant predictor of increased fatigue regardless of DOI. Pain occurred more frequently in incomplete injury.
Szlachcic, Carrothers, Adkins, Waters  (2007)	N = 43  Inc. = 12	16.6 +/- 8	To assess the prevalence of cardiovascular disease via EKG and lipid profiles in	Cross-sectional	Increased DOI was associated with increased EKG changes in persons with abnormal lipid

USA			individuals with chronic SCI.		profiles regardless of completeness of injury.
Ku, Jung, Lee, Park, Shim (2006)	N = 140 Inc. = 106	1-37 $\xi = 16.9$	To explore the risks associated with epididymo-orchitis in SCI.	Retrospective chart review	Increased incidence of epididymo-orchitis was found to occur with increased DOI in incomplete SCI  (risk is related to a specific treatment regimen - clean intermittent catheterization)
S. KOREA					
Drake, Cortina-Borja, Savic, Charlifue, Gardner (2005)	N = 196 Inc. = 37	26-51 $\xi = 33$	To assess aging-related changes in relevant clinical parameters according to method of bladder management in patients with chronic SCI.	Longitudinal (6 years)	Age and DOI are significantly associated with decreasing renal function regardless of neurologic category (including completeness).  Incomplete SCI has a slightly lower risk
UK					

					of UTI.
Ku, Choi, Lee, Jung, Lee, Park, Shim (2005) S. KOREA	N = 179 Inc. = 138	10-53 $\xi = 29.3$	To establish hazard ratios for the risk of complications of the upper urinary tract in patients with SCI in relation to bladder management methods.	Retrospective chart review	The risk of pyelonephritis secondary to vesico-ureteral reflux and renal stones increases with DOI, regardless of completeness of injury.
Garland, Adkins, Rah, Stewart (2001) USA	N = 144 Inc. = 50	12.7 +/- 8.8	To assess the risk factors of age, duration of injury, neurologic deficit and body mass index on the bone mineral densities of the lumbar spine, hip and knee	Cross-sectional	Osteoporotic changes (loss of bone mineral density) in spine hips and knees (excluding the lumbar spine) occurred across the sample, with incomplete SCI's showing less decrease in BMD
Linn, Spungen, Adkins, Bauman, Waters	N = 455 Inc. = 84	16 +/- 11	To determine the expected vital capacity in persons with SCI in relation	Cross-sectional	Longer DOI was associated with pulmonary functional loss

(2001)					
USA				to level of injury, completeness, smoking and DOI as an aid to diagnosis and management of respiratory complications	(measured by FVC). This loss was mitigated by incomplete lesions (in tetraplegia only)
Linn, Adkins, Gong, Waters	N = 222 Inc. = 63	14 +/- 9	To evaluate risk factors for respiratory morbidity in chronic SCI.	Cross-sectional	Decreasing pulmonary function with increased DOI.  Incomplete injury mitigates functional loss in tetraplegia.
(2000)					
USA					
Menter, Weitzencamp, Cooper, Bingley, Charlifue, Whiteneck	N = 221 Inc. = 47	All > 20	To analyze the effects of both age and duration of injury on bowel complications in individuals who have been spinal cord injured for 20 or more years.	Longitudinal	Increased DOI was associated with increased constipation. No significant difference between complete and incomplete injuries relative to constipation and bowel accidents.  Hemorrhoids were
(1997)	**ASIA ABC clustered, inc = D				
UK					

Gerhart, Bergstrom, Charlifue, Menter  (1993)  UK	N 279  Inc. = 84  **ASIA ABC clustered, inc = D	20-40	To assess functional changes over time in long-term SCI. Parameters included fatigue, weakness, pain.	Retrospective	associated with increased age, but not DOI.  Weakness increases with increased DOI, no significant differences between complete and incomplete
Whiteneck, Charlifue, Frankel, Fraser, Gardner, Gerhart, Krishnan, Menter, Nuseibeh, Short, Silver  (1992)  UK	N = 834  Inc. = 271	> 20	To evaluate the lifetime health and functional status of persons spinal cord injured more than 20 years ago, including mortality/morbidity (and psychosocial outcomes, which were not included)	Retrospective	Individuals with incomplete injuries had the highest incidence of neoplasms and cardiac deaths

## **Are you living with a long-term incomplete Spinal Cord Injury?**



**Research Study**

Docket # 14312

The purpose of this study is to describe any changes in physical function that people with an incomplete SCI may have as they go through middle age.

You are receiving this email through your health care provider at the New England Regional SCI Center at Boston Medical Center, who sent this invitation to their email listserv on behalf of the person doing the research study. The researcher did not see your name, address, or any information about you. You are receiving this email because you may have experienced an incomplete spinal cord injury years ago and are now in your “middle years”.

To be eligible for this study you must:

1. Have had a traumatic incomplete spinal cord injury at least 15 years ago
2. Be 35 to 65 years old
3. Be able to read or speak English

If you qualify for this study and decide to participate, you will be asked to participate in one interview:

- Any participant, anywhere in the world, may choose an e-mail interview, meaning you may use e-mail to answer study questions about your experience.
- Participants within about a 2 hour-drive of Boston may choose instead to meet with the interviewer for a face-to-face interview that will last about 90 minutes.

Participants will receive compensation for completing a study interview.

If you are interested in participating in this study or want to learn more,  
please contact Deb Armstrong, RN  
University of Massachusetts Medical School, Graduate School of Nursing:

by e-mail at [Deborah.Armstrong@umassmed.edu](mailto:Deborah.Armstrong@umassmed.edu), or  
by phone at 508.999.9245  
(please leave a message and I will call you back)

**Thank you!**



## **Are you living with a long-term incomplete Spinal Cord Injury?**

### **Research Study**

The purpose of this study is to describe any changes in physical function that people with an incomplete SCI may have as they go through middle age.

To be eligible for this study you must:

4. Have had a traumatic incomplete spinal cord injury at least 15 years ago
5. Be 35 to 65 years old
6. Be able to read or speak English

If you qualify for this study and decide to participate, you will be asked to participate in one interview:

- Any participant, anywhere in the world, may choose an e-mail interview, meaning you may use e-mail to answer study questions about your experience.
- Participants within about a 2 hour-drive of Boston may choose instead to meet with the interviewer for a face-to-face interview that will last about 90 minutes.

Participants will receive compensation for completing a study interview.

If you are interested in participating in this study or want to learn more,  
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by e-mail at [Deborah.Armstrong@umassmed.edu](mailto:Deborah.Armstrong@umassmed.edu), or

by phone at 508.999.9245  
(please leave a message and I will call you back)

Thank you!

## **Are you living with a long-term incomplete Spinal Cord Injury?**



**Research Study**

Docket # 14312

The purpose of this study is to describe any changes in physical function that people with an incomplete SCI may have as they go through middle age.

You are receiving this email through the Greater Boston Chapter of the National SCI Association, who sent this invitation to their email listserv on behalf of the person doing the research study. The researcher did not see your name, address, or any information about you. You are receiving this email because you may have experienced an incomplete spinal cord injury years ago and are now in your “middle years”.

To be eligible for this study you must:

7. Have had a traumatic incomplete spinal cord injury at least 15 years ago
8. Be 35 to 65 years old
9. Be able to read or speak English

If you qualify for this study and decide to participate, you will be asked to participate in one interview:

- Any participant, anywhere in the world, may choose an e-mail interview, meaning you may use e-mail to answer study questions about your experience.
- Participants within about a 2 hour-drive of Boston may choose instead to meet with the interviewer for a face-to-face interview that will last about 90 minutes.

Participants will receive compensation for completing a study interview.

If you are interested in participating in this study or want to learn more,  
please contact Deb Armstrong, RN  
University of Massachusetts Medical School, Graduate School of Nursing:

by e-mail at [Deborah.Armstrong@umassmed.edu](mailto:Deborah.Armstrong@umassmed.edu), or  
by phone at 508.999.9245  
(please leave a message and I will call you back)

**Thank you!**





## Appendix F

### Recruitment Letter from Healthcare Providers

Dear potential research participant,

Docket # 14312

Please consider participating in a research study about aging with a traumatic incomplete spinal cord injury (SCI). The purpose of this study is to describe any changes in physical function that people with an incomplete SCI may have as they go through middle age.

You are receiving this letter from your health care provider (such as your doctor or nurse), who sent this letter to you on behalf of the person doing the research study. The researcher did not see your name, address, or any information about you. You are receiving this letter because you experienced an incomplete spinal cord injury years ago and are now in your “middle years”.

You will not need to travel to take part in this study. This study is completely voluntary and will not affect any medical care you now receive. Your answers will be confidential. You will receive compensation for participation and completion of an interview.

#### **Eligibility Requirements**

- Men and women, ages 35 to 65 years old
- Traumatic incomplete spinal cord injury at least 15 years ago
- Can read and speak fluent English

If you are eligible and choose to take part in the study, you will be asked to describe, in your own words, changes in physical function that you may have experienced as you have grown older. There are two ways to participate in the study:

1. Any participant, anywhere in the world, may choose an e-mail interview, meaning you may use e-mail to answer study questions about your experience.
2. Participants within about a 2 hour-drive of Boston may choose instead to meet with the interviewer for a face-to-face interview.

If you are interested in participating, or if you would like additional information about this study, please contact the nurse researcher, Deborah Armstrong,

by e-mail at [Deborah.Armstrong@umassmed.edu](mailto:Deborah.Armstrong@umassmed.edu), or  
by phone at 508.999.9245.

If you reach my answering machine, please leave a message with your phone number and I will call you back.

Thank you for your consideration,

Deborah Armstrong, RN  
Doctoral Candidate  
University of Massachusetts Worcester

If you have any concerns about this study, please feel free to contact Deborah Armstrong’s study supervisor or the Office of Research at UMass Medical Center on weekdays between 8:30am – 4:30pm.

Study Supervisor:  
Anne Kane, PhD, RN  
[Anne.Kane@umassmed.edu](mailto:Anne.Kane@umassmed.edu)  
508-856-5801

Office of Research  
UMass Medical Center  
508-856-2119

Appendix G

Consent Form

Docket # 14312



UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL

COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS IN RESEARCH

CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

Title: **Transitioning through Middle Age with an Incomplete Spinal Cord Injury:**

**A Qualitative Description of Changes in Physical Function**

Principal Investigator: Anne Kane

Co-Investigator: Deborah Armstrong

Research Subject's Name: \_\_\_\_\_ Date: \_\_\_\_\_

**Invitation to Take Part and Introduction**

You are invited to volunteer for a research study. You are asked to take part because you experienced an incomplete spinal cord injury (SCI) more than 15 years ago, and you are now in your "middle age years." Approximately 12 to 20 people with an incomplete SCI will be interviewed. The study will describe changes in physical function that people with incomplete SCI's experience in their middle age years.

**Purpose of Research**

The goal of this research is to describe the changes in physical function people with an incomplete SCI experience in their middle age years. As a person living with an incomplete SCI, you can offer an "insider" view of any changes in physical function that you have experienced or are experiencing as you go through middle age. Approximately 12 to 20 people with an incomplete SCI will be interviewed for this study.

**Your Rights**

It is important for you to know that:

**Your participation is entirely voluntary.**

**You may decide not to take part or decide to quit the study at any time, without any changes in the quality of the health care you receive.**

**You will be told about any new information or changes in the study that might affect your willingness to participate.**

## **PROCEDURES**

If you choose to participate in this study, you will participate in one face-to-face interview. This interview will last approximately 1 to 1 ½ hours (and no longer than 2 hours). In the interview, the interviewer will ask you questions about your experience of aging with an incomplete spinal cord injury. The interview will be tape recorded.

At the end of your interview, the interviewer will ask you if it is okay to contact you again by telephone or email (your choice) if she needs help understanding something you said during the interview. She will only contact you if you give her permission and if she needs you to explain something from the interview. This will take no more than 10 minutes. You may say yes or no without penalty.

Also at the end of your interview, the interviewer will ask you if it is okay to contact you again by telephone or email (your choice) up to 6 months after your interview. This phone call or email would be to ask for your opinion about some of the early findings from the study. This will take no more than 15 minutes. You may say yes or no without penalty.

## **CONFLICT OF INTEREST DISCLOSURE: NONE**

## **RISKS**

There are no expected risks from being in this study. However, some people may feel a bit distressed as they talk about their spinal cord injury. Before the interview begins, the interviewer will suggest that you write down the name of someone you can talk to if you do feel upset. If you begin to feel upset during the interview, you may tell the interviewer and she will end the interview. Also, if the interviewer thinks that you are becoming distressed for any reason during the interview, she may end the interview.

## **BENEFITS**

There is no direct benefit to you from being in this study. However, your participation may help others with this condition in the future as a result of knowledge gained from the research.

## **REASONS YOU MIGHT BE WITHDRAWN FROM THE STUDY WITHOUT YOUR CONSENT**

You may be taken out of the research study if:

1. The researcher decides that continuing in the study would be harmful to you.
2. The study is canceled by the University of Massachusetts Medical School Institutional Review Board.

## **ALTERNATIVES**

If you decide not to take part in this research study, your healthcare will not be affected in any way.

## **COSTS**

There will be no cost to you from being in this research study.

## **COMPENSATION**

You will receive a \$25 gift card in the mail for participation and completion of an interview.

## **CONFIDENTIALITY**

Your privacy is important to us. Your research records will be confidential to the extent possible. In all records, you will be identified by a code number and your name will be known only to the researchers. Your name will not be used in any reports or publications of this study. However, the UMMS Institutional Review Board and/or their representatives may inspect your medical records that pertain to this research study. We will not allow them to copy down any parts of your identifiable information (e.g. your name) or take any of your identifiable information from our office.

**YOUR PARTICIPATION IN THIS PROJECT IS ENTIRELY VOLUNTARY. YOU MAY WITHDRAW FROM THE STUDY AT ANY TIME.**

**THE QUALITY OF CARE YOU RECEIVE WHERE YOU RECEIVE YOUR HEALTHCARE WILL NOT BE AFFECTED IN ANY WAY IF YOU DECIDE NOT TO PARTICIPATE OR IF YOU WITHDRAW FROM THE STUDY.**

## **QUESTIONS**

Before you sign this consent form, please feel free to ask any questions you may have about the study or about your rights as a research subject. If other questions occur to you later, you may ask Dr. Anne Kane at (508) 856-5801, the Principal Investigator. You may take as much time as needed to think this over. If at any time during or after the study, you would like to discuss the study or your research rights with someone who is not associated with the research study, you may contact the Administrative Coordinator for the Committee for the Protection of Human Subjects in Research at UMMS. The telephone number is (508) 856-4261.

**CONSENT TO PARTICIPATE IN THE RESEARCH PROJECT**

Title: **Transitioning through Middle Age with an Incomplete Spinal Cord Injury:**

**A Qualitative Description of Changes in Physical Function**

P.I. Name: Anne Kane

Subject's Name: \_\_\_\_\_

I understand the purpose and procedures of this research project and the predictable discomfort, risks, and benefits that might result. I have been told that unforeseen events may occur. I have had an opportunity to discuss the risks and benefits of this research with the investigator and all of my questions have been answered. I agree to participate as a volunteer in this research project. I understand that I may end my participation at any time. I have been given a copy of this consent form.

\_\_\_\_\_ Date: \_\_\_\_\_

Subject's signature

**STATEMENT OF PERSON OBTAINING CONSENT**

I, the undersigned, have fully explained the details of this clinical study as described in the consent form to the subject named above.

\_\_\_\_\_ Date: \_\_\_\_\_

Signature of person obtaining consent

**INVESTIGATOR'S DECLARATION**

As the principal investigator or co-investigator on this study, I attest to the following:

- the nature and purpose of the study and study procedures, as well as the foreseeable risks, discomforts and benefits have been explained to the above-named subject
- this subject has been given the opportunity to ask questions and to have those questions answered by knowledgeable research staff
- this subject meets the inclusion/exclusion criteria for this study

I have considered and rejected alternative procedures for answering this research question.

\_\_\_\_\_

PI Signature

Date

Appendix H

Fact Sheet

Docket # 14312



UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL  
COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS IN RESEARCH

**FACT SHEET FOR PARTICIPATION IN A RESEARCH PROJECT**

Title: **Transitioning through Middle Age with an Incomplete Spinal Cord Injury:  
A Qualitative Description of Changes in Physical Function**

Principal Investigator: Anne Kane

Co-Investigator: Deborah Armstrong

Research Subject's Name: \_\_\_\_\_ Date: \_\_\_\_\_

**Invitation to Take Part and Introduction**

You are invited to volunteer for a research study. You are asked to take part because you experienced an incomplete spinal cord injury (SCI) more than 15 years ago, and you are now in your "middle age years." Approximately 12 to 20 people with an incomplete SCI will be interviewed. The study will describe changes in physical function that people with incomplete SCI's experience in their middle age years.

**Purpose of Research**

The goal of this research is to describe the changes in physical function people with an incomplete SCI experience in their middle age years. As a person living with an incomplete SCI, you can offer an "insider" view of any changes in physical function that you have experienced or are experiencing as you go through middle age. Approximately 12 to 20 people with an incomplete SCI will be interviewed for this study.

**Your Rights**

It is important for you to know that:

**Your participation is entirely voluntary.**

**You may decide not to take part or decide to quit the study at any time, without any changes in the quality of the health care you receive.**

**You will be told about any new information or changes in the study that might affect your willingness to participate.**

## **PROCEDURES**

If you choose to participate in this study, you will participate in one email interview. This interview will last approximately 1 to 2 hours of your time, which may be spread out over 2 weeks. During that time, the interviewer will ask you questions by email about your experience of aging with an incomplete spinal cord injury. You can choose to respond to questions at any time that is convenient to you.

At the end of your email interview, the interviewer will ask you if it is okay to contact you again by telephone or email (your choice) if she needs help understanding something you said during the interview. She will only contact you if you give her permission and if she needs you to explain something from the interview. This will take no more than 10 minutes. You may say yes or no without penalty.

Also at the end of your interview, the interviewer will ask you if it is okay to contact you again by telephone or email (your choice) up to 6 months after your interview. This phone call or email would be to ask for your opinion about some of the early findings from the study. This will take no more than 15 minutes. You may say yes or no without penalty.

## **CONFLICT OF INTEREST DISCLOSURE: NONE**

## **RISKS**

There are no expected risks from being in this study. However, some people may feel a bit distressed as they talk about their spinal cord injury. Before the interview begins, the interviewer will suggest that you write down the name of someone you can talk to if you do feel upset. If you begin to feel upset during the email interview, you may tell the interviewer and she will end the interview. Also, if the interviewer thinks that you are becoming distressed for any reason during the email interview, she may end the interview.

## **BENEFITS**

There is no direct benefit to you from being in this study. However, your participation may help others with this condition in the future as a result of knowledge gained from the research.

## **REASONS YOU MIGHT BE WITHDRAWN FROM THE STUDY WITHOUT YOUR CONSENT**

You may be taken out of the research study if:

1. The researcher decides that continuing in the study would be harmful to you.

2. The study is canceled by the University of Massachusetts Medical School Institutional Review Board.

### **ALTERNATIVES**

If you decide not to take part in this research study, your healthcare will not be affected in any way.

### **COSTS**

There will be no cost to you from being in this research study.

### **COMPENSATION**

You will receive a \$25 gift card in the mail for participation and completion of an interview.

### **CONFIDENTIALITY**

Your privacy is important to us. Your research records will be confidential to the extent possible. In all records, you will be identified by a code number and your name will be known only to the researchers. Your name will not be used in any reports or publications of this study. However, the UMMS Institutional Review Board and/or their representatives may inspect your medical records that pertain to this research study. We will not allow them to copy down any parts of your identifiable information (e.g. your name) or take any of your identifiable information from our office.

**YOUR PARTICIPATION IN THIS PROJECT IS ENTIRELY VOLUNTARY. YOU MAY WITHDRAW FROM THE STUDY AT ANY TIME.**

**THE QUALITY OF CARE YOU RECEIVE WHERE YOU RECEIVE YOUR HEALTHCARE WILL NOT BE AFFECTED IN ANY WAY IF YOU DECIDE NOT TO PARTICIPATE OR IF YOU WITHDRAW FROM THE STUDY.**

### **QUESTIONS**

Before you agree to participate, please feel free to ask any questions you may have about the study or about your rights as a research subject. If other questions occur to you later, you may ask Dr. Anne Kane at (508) 856-5801, the Principal Investigator. You may take as much time as needed to think this over. If at any time during or after the study, you would like to discuss the study or your research rights with someone who is not associated with the research study, you may contact the Administrative Coordinator for the Committee for the Protection of Human Subjects in Research at UMMS. The telephone number is (508) 856-4261.

After reading this Fact Sheet, if you would like to participate in the study, please reply to this email to let Deborah Armstrong know that you are interested in being part of the study:

Deborah.Armstrong@umassmed.edu



## Appendix I

### Safety Plan for In-home Interviews

If in-home face-to-face interviews are necessary, local police will be contacted and asked if the area is safe. If the police indicate that the area is unsafe, the researcher will attempt again to make alternative arrangements for a public meeting location or to arrange an email interview, but the researcher will not enter the unsafe area. If the area is reported to be safe, a communication plan will be in place to further ensure the safety of the investigator. The researcher will carry a cell phone with her during each interview. In addition, a colleague or family member of the researcher will serve as a point of contact. Prior to each visit, the researcher will provide the point of contact with a sealed envelope containing the participant's address. Phone contact will be made between the researcher and the point of contact just prior to entering the participant's home, and then immediately upon leaving the home. If a post-interview phone call is not initiated by the researcher, the point of contact will attempt to call the researcher. If she does not answer, the point of contact will contact the police. The envelope will remain sealed unless the point of contact deems it necessary to alert the police. The sealed envelope will be shredded within 24 hours of the interview. The researcher will immediately terminate the interview if she feels that her safety is in question.

Appendix J  
Interview Guide

Aim/Concept	Main Question	Sample Probes
Foundational information	Tell me about your spinal cord injury.	When and how were you injured?
#1 Awareness of changes in physical function	How has your physical function changed in the last several years? How do you see those changes related to your spinal cord injury (or not)?	As we get older, there are certain changes in physical function that we may experience, such as discovering the need for reading glasses, or, for women, changes associated with menopause. (Clarifying the main question). Are there any changes that you have experienced that you believe are related to your SCI?  Tell me about any changes you have noticed recently in your muscle strength.  Explain any changes you have experienced in your ability to walk (if ambulatory post-injury).  Describe any changes you have experienced in your bladder and/or bowel function.
#2 Awareness of timing patterns and/or critical events	Can you recall any abrupt physical changes that you would relate to your SCI?  What about gradual changes?	How would you describe your endurance now compared to 10 years ago?
#3 Knowledge and preparation	What have you been told to expect about the process of aging with your injury?  What have you wanted to know about aging with a SCI?  What are your sources for information about your SCI?  What changes do you anticipate in the future related to aging with an SCI?  Are there any strategies that you have used that might help others with an incomplete SCI with their own physical changes?	What kind of physical changes did you anticipate during middle age? Why?  What physical changes happened that you did not anticipate?  When you have questions about aging with a SCI, whom do you call?  What do you think SCI support groups offer people?  What about other supports from the community?  Why do you think that?  What do you think about the internet as a source of information about aging with a SCI?